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TOWARDS A PROFESSIONALIZATION

OF THE BIOETHICAL EXPERT

IN THE PUBLIC ARENA

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ABSTRACT

In an increasingly specialized world, where the production of knowledge and its acquisition have become a collective enterprise, nobody can master all the fields alone. This has led to the proliferation of a myriad of experts, each of whom is specialized in a precise domain or subdomain. Given this picture, it is not surprising that people with training in bioethics are often referred to as 'bioethics experts' and/or 'bioethical experts'. However, far from being confined to a specific social dimension, in today's society bioethicists are a commonplace presence in an ever-increasing range of domains. In recognition of this phenomenon, the aim of this thesis is to explore the so-called issue of bioethical expertise. This means first and foremost exploring two main questions: whether an expertise in the field of bioethics might actually exist and what are, if any, the skills that the bioethical expert is endowed with, in order to understand whether this figure is on a par with professionals of other disciplines. After presenting a general review of the current literature on this issue and briefly indicating the different research paths this research topic might lead to, the focus will be narrowed to dwell on the main research questions this work aims to address: is there a legitimate role for the bioethical expert within the public arena, and, if so, what is this role? Far from being a straightforward question, this issue is further complicated by a vast literature decrying the threat posed by bioethicists with respect to the broader context in which they operate: liberal democracies. In taking these considerations seriously, this dissertation aims to 'solve the paradox' connected with the figure of bioethical expert and to propose a normative model of bioethical expert which aims to be compatible with the tenets of liberal democracies and, in particular, their public decision-making processes. This figure will be defined here as *the facilitator of deliberation*, thus recognizing the debt it has towards the political theories of deliberative democracy.

This work is structured as follows: first of all the theoretical current debate concerning the topic of bioethical expertise is presented. Secondly, by narrowing the focus of

investigation I concentrate on the domain in which the bioethical expert proposed here has to operate: public bioethics. The normative proposal of bioethical expert as facilitator of deliberation is then presented, remodelling the former in relation to the already existing figures occupying the public arena. Finally, the results of a preliminary experiment, designed to empirically explore this new figure, are presented and discussed.

INTRODUCTION

1. Preamble

In the world of today bioethicists are a commonplace presence in an ever-increasing range of domains. They sit on local ethics committees evaluating the ethical tenability of research protocols, they work at a higher level in national and international bioethics commissions endowed with advisory power (with the mandate to provide ethical consultations to the institutions where they work), they teach bioethics and subjects akin to bioethics in universities; furthermore, they visit hospital wards to provide both patients and healthcare professionals with ethical suggestions in order to facilitate the taking of complex clinical decisions. In all these settings, bioethicists are given the power of distinguishing the *good* from the *bad* and to indicate the best way to go. But this, then, leads us to ask on what basis is the power granted to them legitimate. Are there some justifiable and tenable reasons for granting bioethicists not only an advisory but also a *decisional* role?

All these questions revolve around the issue of *bioethical expertise*, which is one of the core problems of contemporary foundational bioethics. However, the parameters of the investigation of bioethical expertise are not easy to identify. This is not just because it is a complex foundational issue, but also because its very meaning varies, depending on the perspective of analysis adopted and, above all, on the type of questions we pose. Therefore, in order to explain what addressing the topic of bioethical expertise means, we should first define what questions we want to ask.

2. Plurality of questions

In the literature, usually three groups of questions dealing with the topic of bioethical expertise might be identified. This work differentiates between them as follows: the conceptual questions of bioethical expertise, the "authority" questions of bioethical expertise and the political questions of bioethical expertise.

The conceptual questions on bioethical expertise are strictly foundational and epistemological questions, as they are concerned with the investigation of the conditions of possibility of an expertise in the field of bioethics and in the analysis of the epistemological status of bioethical knowledge. More specifically, these questions are concerned with whether something like an expertise in the field of bioethics might actually exist, the nature of its content, and what kind of knowledge bioethics might convey (Weinstein 1994; Steinkamp & Gordijn 2001, 2008; Rasmussen 2005; Varelius 2008; Schicktanz *et al.* 2012).

The "authority" questions on bioethical expertise shift the attention from the concept of bioethical expertise to the one of *bioethical expert*. Indeed, these questions concern the professional figure of the bioethicist and, in particular, the understanding of who, between philosophers or non-philosophers, is most entitled to be defined as a bioethical expert. The answer to this set of questions follows from the individuation of the specific core of competences a bioethical expert is supposed to have, and with the subsequent identification of which professional figure most likely possesses them (Archard 2011; Gordon 2014; Gesang 2010; Cowley 2012).

Finally, *the political questions on bioethical expertise* are also focused on the figure of bioethical expert rather than on disciplinary and foundational issues. However, in contrast with the "authority questions", they go further: they explore the actual role bioethical experts fulfil in a democratic society, by focusing on whether their power should be restricted or increased according to the principles of liberal democracy (Moore 2010 and 2012). The ultimate aim is to propose normative models of the bioethical expert compatible with democratic decision-making procedures.

3. Plurality of roles

In conjunction with the aforementioned plurality of questions, the investigation of the topic of bioethical expertise is further complicated by the plurality of settings in which bioethicists currently operate: the academic setting, the health care setting, and the

public/political one. Indeed, as mentioned in the preamble, bioethical experts are usually academic professors teaching bioethics (or moral philosophy, broadly speaking), acting in parallel as members of advisory ethics committees, both in research institutes and governmental institutions, or working as ethics consultants in medical centres, supporting physicians and health care professionals in the clinical decision-making process. Precisely this plurality of settings prevents the basic definition of the role of the bioethical expert in a conclusive manner, as it depends on the specific domain in which each expert operates. In other words, once the kind of questions that need addressing have been established, a second choice needs to be made: identifying the type of expert one wants to focus on, whether the academic teaching bioethics, the ethics consultant, the member of the IRBs and/or the Ethics Committees, the member of Advisory Commission Boards at a national or international level.

Therefore a proper exploration of the issue of bioethical expertise should first and foremost specify whether it is interested in examining either the concept of bioethical expertise or the figure of bioethical expert. In the latter case, it should be clarified whether such an analysis is interested in understanding what educational training is more suited for fulfilling the professional role of the bioethicists[1], or whether the analysis should focus on the compatibility between the expert and the principles of liberal democracies. Finally, in both of these two last scenarios, it should be specified what kind of bioethical expert is to be focused on, since, for example, the competences required of the professor of bioethics might be profoundly different from the ones of the ethics consultant dealing with clinicians and/or patients.

4. Why is the issue of bioethical expertise relevant?

[1] The terms "bioethical expert" generally considered and "bioethicist" will be used in an interchangeable way.

[2]Amongst the International Guidelines and Declarations, there could be mentioned: the Nuremberg Code (1947), the Declaration of Helsinki (1964), the Convention on Human Rights and Biomedicine (the so-called Oviedo Convention, 1997). For the ethical principles regulating human research see: Beauchamp, Tom L., and James F. Childress. *Principles of Biomedical Ethics. Seventh Edition*. Cambridge, MA: Oxford University Press, 2013.

[3] One might wonder why the political framework to which the expert is related is the one represented by Western liberal democracies, that is, why the former should be accepted as long as it is compatible with the principles, tenets, and ideals of the latter. Another way to frame a quite similar question is to ask how such an

4.1 Power granted to bioethical experts

Whatever the content of bioethical expertise is, and whatever role bioethical experts might have in our contemporary societies, there are some considerations that show why the issue of bioethical expertise is worthy of investigation. Irrespective of whether they are equipped with a specific expertise, bioethical experts are actually considered as *authoritative sources of knowledge* on ethical matters, and therefore increasingly entrusted with political and decisional authority by the community in general and by institutions in particular. In other words, the presence of bioethical experts in our societies is expanding at different societal levels, even if what constitutes their expertise is neither uncontroversial nor so easily defined. Moreover, bioethical experts are not democratically appointed public officers, but rather professionals for hire.

These considerations lead us to ask on what grounds bioethicists' power is granted – namely the *justification* of its *legitimacy*.

4.2 What is the future for bioethics?

This last question appears more relevant and even pressing going back and looking at the reasons that prompted the origin and development of bioethics. Amongst these reasons, there is clear evidence of abuses of human subjects in the name of pioneering biomedical research, the increasing technological power in the context of human and non-human life and the transformation of the patient-physician relationship as a consequence of the emphasis on the value of autonomy (Callahan 1973, Jonsen 1998, Evans 2002, Kovács 2010). However, if we look closely at the aforementioned aims, we can see that most (if not all) of them have been already reached. For example, the abuses of human subjects in the context of biomedical research have been considerably reduced thanks to the creation of international ethical guidelines, codes and principles regulating the biomedical research on human subjects[2] and the creation and reinforcement of the ethics committees.

[2]Amongst the International Guidelines and Declarations, there could be mentioned: the Nuremberg Code (1947), the Declaration of Helsinki (1964), the Convention on Human Rights and Biomedicine (the so-called Oviedo Convention, 1997). For the ethical principles regulating human research see: Beauchamp, Tom L.,

Moreover, even if a paternalistic attitude is still adopted in some environments, the autonomy-based paradigm, although in different formulations, is now widely accepted and followed both at a clinical and research level. Once we have become aware of the fact that the reasons for the creation of bioethics no longer exist, we might ask ourselves why we still need bioethicists or, at least, why grant them ever more decisional power and public recognition. In other words, if the reasons that originally justified the creation of the discipline are evident, the justification of bioethicists' *current* power is not so clear and sometimes is explicitly rejected. Therefore what are the tasks contemporary bioethics should fulfil (Ashcroft 2010)?

Exploring the topic of bioethical expertise thus opens several research paths: from the examination of the *epistemological status* of bioethics (Reichlin 1994) – namely, is bioethics a discipline? What kind of discipline? Directed towards what kinds of aims? – to the analysis of some practical issues concerning the *professionalisation* of bioethics experts (Picozzi *et al.* 2003) – namely, the potential contributions bioethicists as professionals might specifically make in their respective fields of investigation. Whatever the specific focus of the investigation, it is nonetheless clear that such an endeavour goes to the very heart of bioethical enterprise.

5. My perspective

5.1 The bioethical expert within the public arena

Taking into consideration the multiple layers and dimensions characterizing the topic of bioethical expertise, this research project focuses on a specific set of questions – the previously defined *political questions of bioethical expertise.* This means, as I mentioned before, investigating the role of bioethical experts within the public arena, conceived here as that 'discursive space' which is produced and framed by the public interaction between free and equal citizens looking for fair terms of cooperation, while discussing on matters of public interest.

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and James F. Childress. *Principles of Biomedical Ethics. Seventh Edition*. Cambridge, MA: Oxford University Press, 2013.

As such, the enactment of the public arena hinges on certain features. First of all, these discourses should take place ideally into a *public space*; such a space might be considered as public just metaphorically, but it can also acquire material currency and physical instantiation in institutional spaces (such as public forums, juries, etc.). Secondly, citizens' *attitudes* should be genuinely oriented towards the pursuit of the so-called public good. This means not only that purely self-oriented interests are considered illegitimate within such a space, but also that public-spirited perspectives should be endorsed and highly promoted by the side of citizens. In addition to this, some considerations regarding the *content* of public discourses seem to deserve some attention here. In particular, the conceptualisation of the public arena as a discursive space is in turn bound to the consideration that such discourses pertain matters which are publicly relevant. This concept might be interpreted in a twofold manner: on the one hand discourses are relevant from a public standpoint because they provides citizens with the chance to formulate and refine their opinions on public matters, while, on the other, they are relevant because they constitute the starting point for building novel (or revising already existing) laws and policies on issues of public interest. Finally, public arena is that social space which accepts as valid only some *discussing* and *decision-making methodologies*, while rejecting some others as illegitimate from a public standpoint (as it will be shown in chapter 2).

The fundamental reason lying behind the choice of focusing on the role of bioethical expert in the public arena is that such an analysis, although particularly relevant, is almost totally lacking in the contemporary debate. Indeed, while several attempts have been made to defining once and for all the content of such an expertise (Weinstein 1994; Steinkamp, and Gordijn 2003, Steinkamp *et al.* 2008; Rasmussen 2005; Varelius 2008; Schicktanz *et al.* 2012), as well as the role of the bioethical expert in clinical and research contexts (Steinkamp, Gordijn and ten Have 2008; Rasmussen 2011), the examination of such a topic in this setting is largely absent in the literature.

The imbalance between the attention paid to experts in some settings to the detriment of others might be partially explained by considering the importance granted to ethical reflection in these respective domains. To be more precise, the growing ethical sensitivity that is increasingly pervading both clinical and research settings does not appear to have a clear correspondence in the public setting. This does not mean that the importance of an ethical reflection is absent or explicitly rejected. On the contrary, the recognition by politicians and institutions' representatives of the importance of ethics and its leading values (transparency, integrity, attention to citizens' needs, etc.) is often held up as part of a public rhetoric. However, in reality a focused attention to the ethical issues is rare and, if present, mainly appears in unstructured and non-standardized ways.

5.2 Public bioethics and deliberative democracy

Taking into consideration what has been outlined so far, the main purpose of this work is to propose a normative model of bioethical expert within the context of public decision-making, compatible with the tenets of liberal democracies[3]: i.e. a model of public bioethicist, specifically devoted to public ethical issues. In other words, the idea is to professionally rethink the bioethicist *in* the public, and *for* the public[4]. This work will

[3] One might wonder why the political framework to which the expert is related is the one represented by Western liberal democracies, that is, why the former should be accepted as long as it is compatible with the principles, tenets, and ideals of the latter. Another way to frame a quite similar question is to ask how such an emphasis on the political framework of liberal democracies is justified. The answer to these questions is twofold. First of all, I am explicitly endorsing this political viewpoint as my background assumption. In other words, far from being interested in the analysis of the bioethical expert within several political domains, I intentionally focus on a specific political environment, since I think that the kind of questions under investigation in this work cannot avoid being referred to a specific political context (which has been here identified in the figure of liberal democracies). The second reason lying behind this choice should be found within the current debate on bioethical expertise and in the way in which the latter has been structured. In particular, as it will be shown in Chapter one, most of the resistance towards the act of granting ever more power to bioethical experts is related to the challenge they seem to pose to the tenets of liberal democracies. In other words, the issue of bioethical expertise (embedded here in the figure of bioethical experts) is rejected mostly for its being related to a broader issue, that is, the controversial relationship between expertise and democracy. Precisely because of this reason, an investigation specifically devoted to the exploration of such an alleged dichotomy seems particularly urgent within the debate.

[4] In order to prevent the reader from potential misinterpretations, it seems important to explicitly clarify the level of analysis adopted here while speaking of 'public bioethics'. As it will be explained in Chapter three, by public bioethics I mean the whole range of bodies and procedures such as national ethics councils, parliamentary ethics commissions or public consultations on 'ethical issues' that are meant to inform and guide political decision-making with respect to ethical considerations, at a *national* level (Kelly 2003; Moore 2012). In other words, far from being interested in the actual or potential management of public ethics issues at an international level, this work mainly focuses on *national bioethics commissions* and the public arena as formerly depicted.

define this model "the facilitator of deliberation", as it combines the ideals and procedures of deliberative democratic theories (Gutmann and Thompson 1996; Gutmann and Thompson 2004) with the main characterizing features of the interdisciplinary practice of the facilitation. Although some authors would deny that expertise (and bioethical expertise above all) can coexist with democracy, this work will strive to defend the argument that, when properly designed, the role of bioethical expert is valuable and compatible with democratic (and deliberative democratic) conceptions of collective decision-making.

5.3 The methodological approach

The methodological approach that will be used in order to devise the model defined as "the facilitator of deliberation" is a combined approach, made up of two different methodological sub approaches, that will be defined here as an *upstream approach* and a *cross-disciplinary approach*.

The definition of the former lies upon the fact that its starting point, far from being the theoretical debate framing the issue of bioethical expertise, is the consideration of the decision-making processes that might be adopted at the public level. This first methodological choice is justified as follows: the traditional way of addressing the debate does not appear particularly appropriate for our purposes, since it looks at this issue from too general a standpoint – the issue of bioethical expertise and not the figure of the bioethicist involved in the public setting. By contrast, the idea conveyed here is that, if we want to propose a professional figure that is to some extent at the service of the public, we should begin precisely from the examination of this context and its needs with respect to bioethically relevant issues. In other words, if the focus of the proposal is a normative model of the bioethicist integrated in the public arena, this last setting should be specifically analysed in order to decide how to shape such a figure so as to improve the former.

Once established what the starting point of the analysis should be, the next question is to ask how public decision-making should be legitimately carried out in cases of mutually-

binding decisions involving bioethical issues. With regard to this last question, this work attempts to find an answer in the so-called theories of deliberative democracy and, more precisely, in their analysis of the process of public deliberation. Precisely this reason leads to the definition of our methodology also as 'cross-disciplinary', since it borrows some methodologies and practices usually belonging to the fields of political theory and political science and implements them into the field of public bioethics. In other words, this work links the traditional debate on public bioethics and the political theories of deliberative democracy in order to defend a novel view of the bioethical expert in the context of decision-making as the *facilitator of deliberation.* By doing so, the bioethical expert will be a new professional role, potentially able to build a bridge between bioethical knowledge and the needs of non-experts.

6. Structure of the thesis

This work is divided into two main parts: a theoretical part and an experimental part. Starting from a theoretical review of the general debate of the topic of bioethical expertise, the purpose of the first part is to present a normative account of the bioethical expert within the context of public bioethics compatible with the tenets of liberal democracies. The second part is aimed at putting this normative proposal to test, by empirically analysing this new figure by means of a lab experiment, specifically devised as to serve this purpose.

The first part of this work is structured as follows: in the first chapter a systematic review of the literature will be provided in order to help the reader to familiarise himself/herself with the complex debate of bioethical expertise. In particular, the main objections to the existence of bioethical expertise and to the validity of bioethical experts as legitimate professional figures will be properly addressed and debunked. The consideration that these objections are not definitive and, hence, that a bioethical expertise and bioethical experts can exist, will lead to the presentation of the main definitions of bioethical experts and to the most widely accepted theory of bioethical expertise, the so-called "standard argument". This work being interested in *public bioethics*, the second

chapter narrows the analysis, focusing on the examination of the domain where the bioethical expert as we conceive it should operate. By exploring the most common public decision-making models – namely aggregation and deliberation – I will aim to ascertain which of the two can be considered more legitimate for public bioethics. Secondly, I will present some attempts to interpret public bioethics as a specific way of implementing deliberative democratic ideals. Then, I will narrow the focus of investigation by presenting some more concrete ways in which deliberation has been implemented – the so-defined *mini-publics* – so as to present the scenario in which our bioethical expert might operate. In particular, it will be explained that several attempts to test the deliberative ideals have already been done, but that a very few of them regard bioethically relevant topics. The third chapter discusses the theoretical role and functions ascribed within the literature to the *deliberative moderators*, who are those figures managing deliberation within mini-publics and that represent the starting point for the definition of the bioethical expert presented here. The final aim of this chapter is to present the core argument of this work: the rethinking of the bioethical expert as the *facilitator of deliberation*. In particular, after explaining to what extent the facilitator is asked to possess not only a procedural but also a substantial expertise, the main roles, tasks and values ascribed to the facilitator are shown. The last part of the chapter focuses on the philosophical justification lying behind such a proposal.

The second part of this work deals with the empirical investigation of this figure. First of all, the *aims* of the experiment that has been carried out will be presented and properly explained. Secondly, all the methodological aspects will be reported, and in particular it will be shown that, in order to ensure a high internal validity while preserving a good external validity, both the choice of topic and sample were defined on the basis of two complex preliminary analyses. These comprised a field study evaluating the preferences of undergraduate students on a range of bioethical topics of public interest and a demoscopic analysis measuring the preferences of the general population on the same. Thirdly, the

design of the experiment and its detailed daily programs will be described. Fourthly, the results of the experiment will be presented and analysed, with particular reference to their repercussions on the normative proposal of bioethical expert advanced here. Finally, some suggestions concerning the practical placement of this figure will be made.

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CHAPTER ONE

Why having experts? And why not?

1. Introduction: defining expertise

In a specialized world, where knowledge has increasingly become a collective enterprise, nobody can master all the fields. This has led to the generation of a myriad of experts, each of whom is specialized in a precise domain or subdomain (Rasmussen 2005). The definition of experts, generally considered, does not seem particularly controversial. An *expert* is someone who possesses a proficiency in a specific domain. This, in turn, has been quite unanimously interpreted as equivalent to the possession of some knowledge and skills in a specific limited professional field. However, the opinion as to whether such a knowledge should be just superior (Steinkamp, Gordjin and Ten Have 2008) or even exclusive (Ericsson *et al*. 2006) in order to consider its possession as an expertise, varies from author to author. Moreover, having an expertise seems to differ from possessing a *competence*, since the former is a broader concept involving both knowledge and skills, while the latter is a narrower concept just limited to skills (Steinkamp, Gordjin and Ten Have 2008). Starting from the consideration that expertise deals with skills and knowledge, but that these two features characterize expertise in a very different manner, two kinds of expertise have been identified: the *performative* expertise and the *epistemic* expertise (Weinstein 1993). An individual is an expert in the performative sense if he/she is able to perform the skills related to the specific domain of expertise in an effective and proper way. In contrast, an individual is an expert in the epistemic sense if he/she is able to offer strong justifications for a set of propositions in a specific domain. Hence, the performative expertise deals with the act of doing something well in a specific domain, whereas the epistemic expertise deals with judgment and with the theoretical capacity of properly justifying the positions belonging to their specific area of expertise. Within this very last

account "a claim is an 'expert opinion' if and only if it is offered by an expert, the expert provides a strong justification for it, and the claim is in the domain of the expert's expertise"[5] (Weinstein 1993, 58).

Given this picture, it is not surprising that people with training in bioethics are often referred to as 'bioethics experts' and/or 'bioethical experts'. However, as already pointed out in the Introduction, the question "who is the bioethical expert?" does not appear so easy to answer. Such a difficulty is arguably ascribed to several reasons, two of which deserve particular attention here. The first one deals with the controversial nature of bioethical knowledge together with its potential consequences, such as *lack of widely accepted standards*, *distrust towards experts*, as well as *disagreement between them*. The second reason has to do with the negative consequences that could follow from the presence and permanence of bioethical experts in our societies in terms of *non-experts autonomy*, *judicial independence* and *equality*. Therefore, if the first set of reasons aims to demolish the concept of bioethical expertise, the second one tries to show the incompatibilities between the bioethical experts as professionals and the grounding ideals of liberal democracies.

This chapter is structured as follows: first of all, the two sets of arguments against bioethical expertise and bioethical experts will be presented and properly addressed (§2 and §3). By doing this, I will show to what extent these objections are not definitive and why they leave the door open both to the existence of bioethical expertise and to bioethical experts as legitimate figures if interpreted in some specific ways (§2 and §3). Secondly, the current dominant view of bioethical expertise and the main interpretative accounts of bioethical expert will be presented (§4). Finally, I will show what elements of these

[5] On the topic of expertise generally speaking see: H.M. Collins and Robert Evans, *Rethinking expertise*, University of Chicago Press (2007); H.M. Collins and M. Weinel, "Transmuted expertise: How technical non-experts can assess experts and expertise". *Argumentation* 2011, 25(3), 401-413; A. Gelfert, "Expertise, argumentation, and the end of inquiry". *Argumentation* 2011, 25(3), 297-312; J. Goodwin, "Accounting for the Appeal to the Authority of Experts". *Argumentation* 2011, 25(3), 285-296; G. Kutrovátz, and G. Á. Zemplén, "Experts in Dialogue: An Introduction". *Argumentation* 2011, 25(3), 275-283.

theories will be taken into account in order to develop the proposal of bioethical expert in its public role within democratic societies (§5).

2. Objections to bioethical expertise

2.1 The lack of consensus argument: disagreement amongst bioethical experts

One of the most important objections raised towards the idea that a bioethical expertise can actually exist is connected with the observation that bioethical experts disagree among themselves about what constitutes a correct behaviour, a good life, the most legitimate solution to ethical dilemmas, etc. (Bambrough 1967). If the potential candidates for the title of bioethical expert disagree on the constitutive features of their discipline and on its content, how can we decide who the real experts are? This objection has been articulated in different ways. On the one hand, it has been claimed that, even if some layers of disagreement are also present in other disciplines, the disagreement surrounding ethical issues is qualitatively different and/or deeper – some would say "more intractable" (Cowley 2005) – than the one present in non-ethical disciplines. In the words of Ruth Shalit, people endorsing this view would say that "The surgeon's recommendation rests on an agreed-upon set of facts and criteria […]. The philosopher's recommendation depends on a set of criteria that is not agreed upon, but varies from culture to culture and, more and more, from individual to individual. One man's categorical imperative is another man's heresy" (Shalit 1997, 24). One the other hand, other scholars have put forth the idea that agreement between the experts of a discipline has to be considered as the necessary condition for the existence of the discipline itself (Bambrough 1967). However, since (bio)ethics has always been dominated by disagreement amongst those who declare themselves as bioethical experts, bioethical expertise cannot exist (Bambrough 1967).

Three counter-objections against "the lack of consensus argument"[6] might be raised. The simplest way to counter this objection is to show that disagreement is pervasive to all

[6] Both the expressions "lack of consensus argument" and "lack of factual basis argument" have been taken from the paper of Steinkamp, Gordjin and Ten Have (2008). Following this terminological choice, the other objections have been defined accordingly.

academic fields, which means that it is a common feature between experts of several disciplines. Moreover, it has been observed that the degree of disagreement often attributed to ethics is exaggerated, and that disagreement within this field could be even less extreme than in others[7]. Finally, it could be argued that even if we were unable to debunk the claim that the ethical domain is dominated by perennial disagreement, agreement between experts has never been demonstrated as a precondition of expertise.

2.2 The lack of standards argument: lack of clear identification standards

A second objection raised towards the existence of bioethical expertise is that, differently from other professional fields, where there are standardized institutional paths for defining and legitimizing those actually belonging to the field, bioethics as a professional domain of knowledge lacks clear and, above all, unique identification standards (Suter 1984).

The fact that there is no unique and institutionalized *cursus honorum* that those aiming at becoming bioethical experts should go through is certainly true[8]. However, on the one hand, this appears partially related to the controversial nature of the epistemological status of bioethical enterprise. Indeed, the presence of different but equally valid answers to the question "What is bioethics?" and, mainly, "What is the purpose bioethics aims to reach? What are the tasks bioethicists are asked to fulfil as professionals?" seems to explain, and even legitimize, the absence of a unique professional training that should characterize the experts in this field. On the other hand, it could be replied that there is a sort of certification coming from those disciplinary boundaries practically instructed. Indeed, certificates, degrees, masters but, above all, publications on peer-reviewed specialized journals and as well as participation in widely known bioethical conferences, can be considered at least preliminary criteria for distinguishing those who surely cannot be

[7] McConnell, for example, shows that even if supporters of different methods of applied ethics, such as deontologists and utilitarians, but also act utilitarians and rule utilitarians, would surely disagree concerning *the reasons* supporting different moral rules, they would share much more moral rules than the ones non-ethicists would be willing to admit (McConnell 1984, 206-207).

[8] Actually, we might argue that this claim is only partially valid. Indeed, even if it is true that bioethicists might have very different backgrounds (philosophy, medicine and law are the most common ones), a homogenisation regarding specialised educational paths can be nevertheless present.

considered as bioethical experts from those who might enter in this category (Archard 2011).

2.3 The lack of trust argument: lack of trust towards bioethical experts advice

A third objection raised towards the existence of bioethical expertise can be ground in the lack of trust that non-experts show with respect to bioethical experts' expertise. The supporters of this line of though claim that bioethical expertise does not exist since, unlike all the other fields where non-experts are prone to follow experts' advice, in the (bio)ethical domain, the unwillingness of non-experts to follow the advice of bioethical experts is generally observed (Archard 2011). To give an example, patients that are also non-experts in medicine, are usually prone to recognize the expertise of physicians when providing medical advice. This means that very rarely non-experts in medicine would question, for example, the diagnosis, the prognosis or the therapeutic option provided by physicians[9]. Differently, suggestions and/or advice concerning bioethical issues provided by bioethical experts do not usually receive a higher consideration just because they are provided by experts in the field, but could actually appear annoying and even illegitimate.

Actually, even if this objection might appear very interesting from a sociological standpoint, it nevertheless does not seems philosophically decisive. Indeed, even if the recognition of expertise provides non-experts with good (even if not sufficient) reasons to follow expert's advice, the mere fact that non-experts do not recognize bioethical experts' expertise cannot be necessarily interpreted as a signal of the latter's lack of expertise (Archard 2011).

2.4 The "lack of factual basis" argument: (bio)ethics as a subjective field of knowledge

All the aforementioned objections are simply possible ways through which the doubts towards the professional stance of bioethicists could be properly engendered. However,

[9] Actually, the analogy with the medical domain is not altogether fair. As the Stamina and Di Bella' cases (just to quote the most famous ones) have shown, there is an always growing sceptical attitude also towards the medical profession.

there seems to be a deeper reason lying behind all of these doubts, that is, that (bio)ethics, also intuitively, seems *qualitatively* different from non-ethical kinds of expertise. To give an example, having an expertise in climbing seems easily definable, even if we are not experts, and different modalities (indoors and outdoors, on natural and manmade structures) and types (rock, ice, and rope) of climbing could be identified. In contrast, the profound and apparently unavoidable disagreement characterizing ethical matters makes the definitive identification of the bioethical expertise a very complex task. The intuitive feeling that the controversies surrounding ethical discussions are of a different kind from the ones characterizing other domains of knowledge, when further analysed, has been explained by pointing out the impossibility of finding an objective ground from which ethical judgments might be unequivocally made. Using again the example of climbing, even if a disagreement over how to climb a mountain exists, this would no longer be comparable to the disagreement characterizing the debate over the ethical acceptability of abortion and/or euthanasia. According to the supporters of this view, the qualitative gap between (bio)ethics and non-ethics domains might be ascribed to the different kind of contents they deal with. More specifically, (bio)ethics deals with values and not with facts; and since facts are assumed to be objective, whereas values are considered as subjective, facts might be universally true, while values depend upon the specific individual holding them. As a consequence of this line of thought, ethics (and *a fortiori* bioethics) is not an objective field of knowledge. This, in turn, prevents the existence of a uniform and genuine expertise in the field of (bio)ethics (McConnell 1984; Cowley 2005; Varelius 2008)[10].

This objection has been formulated in many different ways, amongst which two appear here particularly relevant.

[10] This first observation does not constitute an objection towards the idea that there might be someone who possesses an expertise in the academic field of bioethics, that is, someone who demonstrates a certain degree of knowledge of the major bioethical theories, approaches and topics. On the contrary, this first observation, if valid, would deny that the bioethical expert is someone who is significantly better at formulating moral judgments, that is, at determining what should be done. For a better systematization of this distinction see Rasmussen (2011) and Vogelstein (2015).

The very first formulation of this critique should be attributed to Terrance McConnell (McConnell 1984). In one of his pioneering works, by assuming that in order to have an expertise in a specific domain this domain has to be objective, he argues in favour of the definition of ethics as a subjective field of knowledge. In particular, he claims that "a matter is objective if there are correct and incorrect answers to questions arising from it" (McConnell 1984, 195). If this general criterion is applied to ethical domain, it follows that ethics can be considered objective only insofar as, in cases of disagreement about ethically legitimate options, we are able to say that at least one, among several, is surely wrong (McConnell 1984, 196). Hence, (bio)ethics, at least allegedly, cannot be considered as an objective field of knowledge since there is no objective ground able to legitimize the distinction between right and wrong and to grant that, between two opponents, one is surely wrong[11]. A different way of formulating this objection has been pursued through the analogy between ethics and science. According to the supporters of this view, since the most exemplary paradigm of objectivity is science, (bio)ethics could be considered as an objective field of knowledge provided that it can take on the characteristics of scientific disciplines. However, since science deals with factual matters while ethics deals with personal perspectives (Shalit 1997; Cowley 2005), ethics cannot be considered as an objective discipline at all.

Several counter-objections could be provided to the "lack of factual basis argument" in both its formulations. First of all, the very notion of objectivity itself is far from being unproblematic. Indeed, the ongoing metaethical debate precisely addresses the problem of the existence of moral facts. Moreover, this issue does not pertain only to ethics, as the

[11] Actually, McConnell reasoning is not so straightforward. Indeed, he starts setting the aforementioned criterion for objective knowledge, but then he leaves it aside in order to argue in favour of what he defines "a slightly modified version of the no moral expert argument", according to which we should be able to infer the subjective nature of moral knowledge by the fact that there are no such figures as moral experts. At the very end of the paper he arrives at the conclusion that objectivity in ethics (as well as in any other field) does not depend upon the presence of experts, since their role could be also conventionally established. This concept could be better explained through the analogy of wine: even if whether wine tastes good might be ultimately a subjective matter, there are some shared criteria to establish whether the wine is actually good (McConnell 1984, 214-215).

notion of objectivity is problematic even in science (see for example Daston and Galison 2007).

However, let me assume for the sake of the argument that it is possible to argue that some disciplines deal with "objective facts". Even in this case, three counter-objections could be raised. First of all, it is not necessary that objectivity in ethics is of the same kind as in science. Indeed, as some scholars have argued, ethics should not be compared to science, since the two differ significantly: if the latter deals with factual evidence, the former deals with justificatory reasons (Yoder 1998). Secondly, even if we assumed that this answer fails to reply to the criticism, since "the reasons in question are supposed to be just as objective as the facts they are meant to replace" (Cowley 2005, 275), this critique is not altogether fair. Indeed, there are positions within the debate, such as metaethical realism and metaethical naturalism that would claim that moral facts actually exist (Boyd 1988; Sturgeon 2002). Finally, even if we agreed that science is the exemplary case of objectivity, and therefore that ethical judgments should be comparable to factual evidence in order to be objective, it can be shown that science is value-laden too (Longino 1990; Douglas 2000).

Finally, the two formulations of this objection lie on a very robust assumption, which is not further justified: that expertise requires objectivity (McConnell 1984). However, if we accept McConnell's assumption, we should be forced to deny that a lot of professionals that we consider as experts are actually as such. As a matter of fact, we usually recognize the possibility of expertise also in areas where it seems we do not have objective knowledge. For instance, we are willing to recognize that there are such professional figures as history of art experts and art critics even if an objective definition of "beauty" as well as of "masterpiece" is clearly missing.

3. Objections to bioethical experts

3.1 The no solutions-based argument: lack of decisive and unequivocal solutions to bioethical dilemmas

One of the main objections to the idea that some professionals in (bio)ethical disciplines exist is rooted in the observation that bioethical experts, even if labelled as such, are not able (or, at least, no more than laypeople) to provide straightforward and unequivocal solutions to moral dilemmas[12] (McConnell 1984, 201). The specific conception of 'expert' defended by the supporters of this objection clearly refers to experts as problem solvers. In other words, experts are here those who are able to solve problems arising in their specific fields of competence. And, what differentiate experts from non-experts is that the former should be able to provide solutions that the latter would not reach by themselves, that is, in a timely and unequivocal way. Hence, since bioethicists (and, generally speaking, ethicists) are neither known for providing useful suggestions concerning ethical matters nor able to solve ethical dilemmas once and for all, they should not be considered bioethical experts.

This critique is easy to debunk. First of all, it could be claimed that the definition of expertise here implicitly endorsed – experts are those who solve problems present in their domains – is neither a formal requisite nor a shared and widely accepted criterion for the attribution of expertise. Indeed, as already mentioned, usually experts are defined by the possession of superior and/or exclusive knowledge in a specific domain that allows them either to better justify judgments within their discipline (the aforementioned *epistemic expertise*), or to perform some skills within their domain of competence (the so-called *performative expertise*). It could be argued that those who criticize the attribution of

[12] By moral dilemma I mean here decisional conflicts occurring within a single agent whenever he/she is asked to take a decision that will end up in the choice of one among two or more courses of actions. Thus, following one would necessarily result in transgressing another. The peculiar feature characterizing moral dilemmas is that the reasons the agent provides in favour of one strategy over another are specifically *moral* reasons, that is, reasons concerning moral principles and values. For a deeper introduction on the concept of moral dilemmas see McConnell T. (2014) "Moral Dilemmas", *The Stanford Encyclopedia of Philosophy*, http://plato.stanford.edu/archives/fall2014/entries/moral-dilemmas. I will distinguish moral dilemmas from ethical disagreements, the latter being defined as conflicts of evaluation between different subjects or groups of subjects, in which each subject or group evaluates the situation differently from other subjects or groups. The decision resulting from that conflict of evaluation usually gives rise to a mutually binding strategy.

expertise to bioethicists do so on the basis of a specific interpretation of performative expertise: in this case amongst the skills the bioethicist should possess, problem-solving occupies a privileged position. However, even if interpreted in such a way, the answer does not appear satisfactory enough because it is not able to explain why problem-solving should be the *conditio sine qua non* for the attribution of expertise, and not just one among other required skills.

A second way to counter this objection is to say that problem-solving goes far beyond the tasks of bioethical experts, since this activity presupposes not just the knowledge of moral theories and principles that should be applied to the specific case in order to solve it, but also the knowledge of the specific non-moral facts that appear nonetheless fundamental for the overall consideration of the dilemma to be faced. And, while the knowledge of what we might call 'moral facts' could be legitimately considered part of bioethical expert's expertise, the same could not be argued for 'non-moral facts' (McConnell 1984, 202-203).

A third way to oppose this objection is to preliminarily accept the problem-solving criterion and to show how paradoxical (or at least counterintuitive) its consequences would be. The final result of this reasoning is the rejection of the criterion itself. More explicitly, if we accept as a criterion for expertise the capacity to provide unequivocal and straightforward solutions to problems arising in the expert's field of knowledge, we would be obliged to acknowledge that almost no one is actually an expert. Consider, for example, the field of medicine. If problem-solving is a valid requirement, physicians should be considered as experts only if they prove to be able to solve patients' medical problems in a definitive and fast manner. However, it happens sometimes that they are in doubt as to what the nature of the patient's medical problem is and, most of the time, even if they eventually solve the problem, this activity could require time and several attempts. Nevertheless, very few people would infer that physicians are not experts in medicine (McConnell 1984, 203).

3.2 The knowledge-shared argument: shared content between experts and non-experts

Another very important objection raised concerning bioethicists as experts of ethical matters, is what has been defined here as "knowledge-shared argument", according to which bioethicists are not experts, since expertise means exclusive possession of a knowledge, and the knowledge possessed by bioethicists is not exclusive at all. This objection has been formulated in many different ways, but two appear particularly noteworthy: "the argument from common rules" and "the argument from common sense morality"[13].

The argument from common rules claims that if the bioethicists' expertise lies in the understanding of moral principles and rules, this knowledge is surely in common with that of non-experts. Those who defend this view claim, for example, that even if bioethicists know the imperatives of not killing, not stealing and not torturing, they are not the only ones to know them. Indeed, most ordinary people, if questioned, would defend the same rules. "Thus, for the most part, philosophers do not want to advocate rules and principles that deviate sharply from the views of ordinary people. It is clear that moral philosophers, *qua* moral philosophers, are not experts concerning factual knowledge […]. It now seems, though, that they are not experts regarding moral rules and principles either. And, if they do not have expertise regarding these, it is implausible that they are moral experts (McConnell 1984, 204)".

The reply to this objection lies in the distinction between the *content* and the *justification* of bioethical knowledge. The idea is that what determines the exclusiveness of ethical knowledge is not the content of such knowledge, but the way in which this knowledge is possessed and justified. And, if the content of ethical knowledge (such as moral rules) might be easily identified both by experts and non-experts, the way in which

[13] The argument from common rules has been presented in other terms by Scoefield *et al.* (1993), whereas the argument from common sense morality has been presented by Archard (2011), but defined in these terms by Vogelstein (2015).

this content (the moral rules) is justified is something in which experts surely surpass non-experts. In other words, bioethicists can justify their beliefs in a way that common people cannot[14]. This is what legitimises their professional stance as bioethical experts (McConnell 1984).

The argument from common sense morality (Archard 2011) partially differs from the argument from common rules, and it is probably the most common and recent defence of the knowledge-shared argument. Since expertise is an exclusionary and restricted concept, and since both philosophers *qua* bioethical experts and non-experts build their reasoning upon common sense morality, we cannot ascribe a specific expertise to philosophers *qua* bioethical experts that non-experts would not possess. In other words moral philosophers are not (bio)ethical experts because they do not possess a particular knowledge, but a knowledge that is possessed by all people (Archard 2011). Three main counter-objections have been provided as a reply to the argument from common sense morality. First of all, John-Stewart Gordon has pointed out that Archard's argument is bound to the acceptance of a premise, without which the entire reasoning falls down: the foundation of moral theory over common sense morality (Gordon 2014). Moreover, as Vogelstein has shown, Archard confused equal access to moral truth with equal liability to it. Finally, even if we might accept that ethical theory is nothing but the systematization of common sense morality, and that bioethical expertise in a strict sense is limited to the clarification of common sense morality, it does not follow that such a clarification and systematization will not prove to be useful (Vogelstein 2014), thus attributing to bioethical experts not so much skills of discovery, but rather skills for collecting and systematizing (which, in turn, could have some discovery potential).

The supporters of the two aforementioned arguments aimed at showing the nonexistence of bioethical experts, highlighting either the incapacity of bioethicists to

[14] Put in this way, this claim leads to the idea that there is a kind of justification that only bioethicists possess and are able to use. Obviously, this is not the case, since bioethicists, in order to justify their positions, use the tools of formal and informal argumentation (and not self-developed tools).

provide straightforward and unique solutions to moral dilemmas, or the shared nature of expert knowledge, which would prevent them from defining themselves as experts in ethical matters. By contrast, two following arguments, rather than aiming at showing the nonexistence of bioethical experts, try to show their illegitimacy. In other words, the arguments that will be presented do not deny that figures like bioethical experts could actually exist, but try to show why their existence as professional figures should be inhibited rather than promoted.

3.3 The slippery slope argument: (bioethical) experts' presence inhibits non-experts judgmental capacities

The third argument against bioethical experts is what is defined here as "the slippery slope argument". This argument aims at showing the slippery slope we might fall down if we promote the flourishing of bioethical experts in our societies. In particular, it claims that relying too much on bioethical experts, as advisors for the solution of moral dilemmas, will prompt the transformation of human agents into moral cripples (McConnell 1984). Indeed, if we get used to relying on experts for every kind of decision concerning the moral dimension, we will become unable to solve those new ethical problems new situations will present us by ourselves, eventually giving up our own autonomy. The idea lying behind this objection is that since ethical expertise is intrinsically different from other kinds of expertise, we cannot, as we do in other cases, relate to experts for the solutions of problems arising in this domain. If, for example, we should completely rely on a physician for the treatment of an illness, the same cannot be said when the problem arises in an ethical context, since we are all required, even if at different levels, to possess some ethical knowledge (McConnell 1984).

Replying to this objection requires showing the limitations of slippery slope arguments in general, and applying these limitations to this specific case. As it has been repeatedly shown, slippery slope arguments are not solid arguments, since their validity cannot be analytically inferred from their premise, but it relies on future projections whose validity

can only be verified in the future. In other words, it could be true that, by relying on experts, common people might in the long run become incapable of making ethical judgments (even the simplest ones) on their own, but this statement cannot be verified in the present. It will be proved to be true if and only if the situation described here can be confirmed in the future. Moreover, it seems plausible to claim that the consequences suggested by this argument can only occur in the case in which agents rely almost totally on bioethical experts (McConnell 1984).

3.4 The inequality based argument: (bioethical) experts within democracies: an oxymoron?

The last and more relevant obstacle to the identification and definition of bioethical experts is that such figures appear in ideological conflict with "the democratic turn" of Western contemporary societies, thus obliging us to profoundly rethink the professional role of the former. According to this explanation, the issue of bioethical expertise, concretely expressed through the presence of experts, appears particularly problematic as it can be considered a specific case of a broader problem: the paradoxical relationship between expertise and democracy. Why is there an incompatibility between expertise and democracy? And why is this incompatibility accentuated when the expertise in question is of a (bio)ethical kind? The answer to this question might be easily provided by the following analogy: why should we allow constitutional courts to decide on the proper interpretation of the constitution, rather than parliaments? The argument for the former is that this is a legal matter that requires a technical competence that members of parliament do not have. Looking beyond this analogy, we could similarly claim that the democratic ideal requiring that any decision influencing the life of a person is taken also by that person, clashes with the exclusiveness inherent in the concept of expertise, and, above all, with the decisional power attributed to it. The inequality-based argument is hence grounded on the incompatibility between expertise and the democratic principle of equality (Scofield 1993; Turner 2001). Understood in this way expertise turns out to be a problem

for democracy since the former "is treated as a kind of possession which privileges its possessors with powers", thus appearing as "a kind of violation of the conditions of rough equality presupposed by democratic accountability" (Turner 2001, 123).

A different and more problematic way of interpreting the relationship between expertise and democracy as an oxymoron arises within the domain of normative political theory, once expertise is defined not in terms of superior knowledge, but of different viewpoint. This variant of the inequality-based argument will be here defined "the state-neutrality argument". If we think of knowledge as a quantity and, therefore, of expertise as a higher quantity of knowledge to which more power is directly connected, we are in front of the already mentioned inequality-based argument. As it will be properly shown in the next paragraphs, this objection can be circumvented either by letting non experts becoming experts, increasing their knowledge through education – the famous and traditional aim of scientists known as "public understanding" – or by separating the two components of the expertise ideal – knowledge and power –, and by arguing that there could be a kind of expertise that, despite requiring superior knowledge, does not provide its possessors with superior power[15]. Differently, if we interpret expertise according to "the state-neutrality argument", things start getting complicated. Indeed, if possessing an expertise means having a different viewpoint with respect to that of non-experts, expertise surely conflicts with the ideal of neutrality generally ascribed to the liberal state. According to this argument, liberal states should exhibit an impartial behaviour with respect to different standpoints and opinions in order to ensure a genuine, fair and open discussion. Hence, since the very concept of expertise assumes that some standpoints count more, expertise is *per se* incompatible with a liberal framework (Turner 2001, p. 124). Therefore, both the inequality-based and the state-neutrality arguments criticize the concept of expertise (as well as the power which follows directly from it) for its inevitable inconsistency with the tenets of liberal democracies, whether equality between citizens or state impartiality is

[15] Both these argumentative strategies will be here conveyed in the proposal of bioethical expert that will be presented in the next chapters.

emphasized. This already problematic relationship appears further worsened if we refer the concept of expertise to the (bio)ethical enterprise, where, as shown earlier, anyone' standpoint seems even more equally legitimate and, therefore, any interference into non-experts' choices appears even less justifiable. To conclude, for many scholars the very idea of an expertise in (bio)ethics violates a central normative intuition of our liberal democracies, namely that on ethical matters individuals should ultimately decide on their own.

This objection, in both its formulations, appears rather problematic to debunk. Indeed, the "binomial" knowledge-power on the one hand, and ethical knowledge-decisional power on the other hand, can be considered as a reasonable observation, worthy of serious consideration. However, what will be shown in this dissertation, mainly devoted to the attempt of breaking up this problematic issue, is that there could still be some legitimate space for bioethical experts within societies as long as this binomial relationship characterizing the concept of expertise is dissolved.

4. The theoretical background

4.1 Preamble: experts vs. expertise and ethics vs. bioethics

What has been said so far is that the growth of knowledge has made a sort of distinction of labour ever more pressing. Such a phenomenon has been put by many at the origin of the creation and proliferation of experts, who are generally defined as those who possess some knowledge and skills in a specific area. This process, as a matter of fact, clearly involves very different disciplines, and of course (bio)ethics too. However, when properly analysed, both the presence of a bioethical expertise and bioethical experts meets some opposition, on the one hand because of the particular nature of bioethical knowledge and, on the other, for the alleged oxymoronic relationship between experts in bioethics and democratic forms of decision-making.

As just shown, neither the objections towards the idea of bioethical expertise, nor those against the existence of bioethical experts have proven to be decisive. This leaves the space

open to some possible interpretations of the concept of bioethical expertise and of the role/s of bioethical experts.

The problematization of these two very complex issues seems to require some preliminary terminological clarifications. First of all, the debate on bioethical expertise appears to be confusingly dominated by the unexplained and interchangeable use of the expressions "bioethical expertise" and "bioethical experts". One might hypothesize that what has been defined here as a confusion is just the presence of the two different lines of investigation characterizing the current literature on this topic, one interested in the *content* of expertise, while the second focused on the *role* of experts. However, this very simple explanation does not seem to be correct, not just because usually there is not a clear distinction between these two levels of exploration (sometimes even within the same study), but also because the connection between the content of bioethical expertise and the role of bioethical experts is definitively unclear. The only connection that clearly emerges is that the disagreement surrounding the professional stance of bioethical experts seems partially bound to the deeper disagreement characterizing the content of bioethical expertise. And, what largely happens in the literature, is that the two levels are so radically overlapped, that some authors, starting from the controversial nature of bioethical knowledge, infer the illegitimacy of bioethical experts; whereas some others, from the potential utility, or even by now inevitable presence, of bioethical experts within our societies, struggle to justify in any possible way the existence of an uncontroversial bioethical knowledge. Secondly, another area of confusion concerns the interchangeably use of expertise/experts in *ethics*, and expertise/experts in *bioethics*. As already pointed out above, even if this distinction could be primarily considered as the proof of the presence of the different disciplinary levels of analysis, the real explanation actually seems to be related to the controversial epistemological status of bioethics as a discipline and to its relationship with ethical theory and moral philosophy in general.

4.2 What is bioethical expertise? The standard argument

In a very recent paper appeared in *Bioethics* in 2014, Eric Vogelstein defines the set of knowledge and skills quite unanimously[16] attributed to bioethical experts by supporters of the bioethical expertise ideal as "the standard argument" (Vogelstein 2014). The standard argument is the dominant theory of bioethical expertise since it is grounded in the dominant explanation of the epistemological status of bioethics: bioethics as applied ethics. According to this argument, originally formulated by Peter Singer (Singer 1972, 1982 and 1988) and then developed by many philosophers with different variations, we might consider that practical ethicists (and, among them, bioethicists) possess some degree of expertise by dint of their competence in moral reasoning. The standard argument claims that bioethical experts possess both skills and knowledge in moral topics. Amongst the skills held by the bioethicists, we might find both some *general* critical-thinking skills and some more *specific* critical thinking skills applied to the ethical domain. As to the formers, we could find the ability to reason formally and consistently, to avoid errors in one's own argument and to detect fallacies when they occur in the arguments of others; as to the latter we have those abilities dealing with the application of these general skills to the moral context, such as, for example, how to apply argumentative tools to moral issues and cases. Concerning the knowledge bioethicists are supposed to have, we might find the understanding of both moral concepts – theories and principles of applied ethics – and moral arguments – as the most important reasons in favour of and against the specific positions related to the traditional topics of applied ethics (Singer 1972, 1982 and 1988; Szabados 1978; McConnell 1984; Ackerman 1987; Brink 1989; Moreno 1991a and 1991b; Weinstein 1994; Crosthwaite 1995; Nussbaum 2002; Sharvy 2007; Varelius 2008; Agich

[16] As explicitly stated in the text, the standard argument (in its different formulations) can be considered as the dominant but not the unique view of bioethical expertise. Even if explicitly referred to the expertise of clinical ethicists, and not to the expertise of bioethicists generally conceived, Steinkamp and colleagues examine two additional "theories" of ethical expertise: the phenomenological account by Dreyfus and Dreyfus according to which ethical expertise refers to an almost totally intuitive moral competence (1991), and the Habermasian-based account rethought by Casarett and colleagues in which the ability of reaching consensus starting from disagreement is considered as the core competence of clinical ethics expertise (1998).

2009). To summarize, according to the standard argument, there is an expertise in bioethics since there are some contents that an expert in the field should know, such as moral theories, accounts, traditions, principles, etc., but also because there are some skills pertaining to the application of such theories and models to concrete situations requiring solutions. Hence, bioethical expertise appears as a concept bound to the belief that there is a core of knowledge – namely what falls into the domain of ethical theory – and a privileged reasoning procedure widely recognized by the vast majority of bioethicists – namely argumentation – for applying this core of knowledge to concrete controversial cases requiring solutions. Actually, despite sounding as an almost homogeneous trend, the standard argument is usually spelled out in very different forms. Indeed, although the emphasis on argumentation leads to the centrality of justification, the way in which justification is interpreted each time deeply modifies the content of the standard account and, therefore, of bioethical expertise. To give some examples, Jan Crosthwaite defines an argument as justified as long as it is supported by reasons, without requiring that these reasons are infallible (Crosthwaite 1995). Yoder makes a step further in the definition of justified reasons, arguing that a position is justified if the reasons supporting it are mutually consistent from a logical standpoint. Therefore, according to Yoder, what matters is not the initial position endorsed by the agent, but the coherence between the agent's moral judgments (Yoder 1998). Finally, Weinstein formulates what can be considered the most demanding version of the standard argument. He considers ethical expertise as a form of epistemic expertise, and in particular, as the normative subdomain of it. Being a kind of epistemic expertise, ethical expertise deals with the capacity of providing justifications within a specific domain rather than with the practical ability of performing some tasks in a proper way. Moreover, dealing with the normative level of investigation, it refers to the prescriptive power of judgments, ideally able to solve dilemmas by providing strong recommendations. As a consequence, ethical expertise is defined as the ability to provide strong justifications for a claim in the ethical domain (Weinstein 1994). Even if he seems

to deny that his account requires the existence of moral objectivity, his idea of strong justification could nonetheless lead to such interpretation[17].

4.3 Who are bioethical experts?

4.3.1 Conceptualizers vs. Problem solvers

The standard argument is the most widely accepted answer to a very specific question: where does the expertise of bioethical experts, if any, lie? Once this question is answered, another question needs to be asked: what follows from this expertise in terms of power and roles granted to them? This means asking where the threshold to experts' power should be set, once their field of expertise has been clearly defined. I would argue that the best way to answer this question could be constructed in the light of the argument proposed by Norbert Steinkamp, Bert Gordijn and Henk ten Have (2008)[18]. Their claim is that those who have tackled the issue of bioethical expertise seem to endorse one of the two following theories: the *narrow theory* of bioethical expertise or the *broad theory* of bioethical expertise.

According to the narrow theory of bioethical expertise, bioethical experts should be considered *conceptualizers of moral issues*. Indeed, because of their ability in formal and argumentative reasoning and knowledge in ethical theories, bioethicists might be more appropriately engaged in a conceptualizing, rather than problem-solving activity. This, in turn, means defining the bioethical expert mainly as a thinker, whose primary task is to define the nature of the problems to be addressed and to take care of the formal analysis of the moral problems and arguments, while remaining detached from the potential practical implementations the case might get to. The argument supporting such a theory is twofold. On the one hand some philosophers have suggested that the majority of moral disputes

[17] See, for example, Yoder 1998.

[18] Actually, by 'bioethical expert' the authors explicitly refer to the clinical ethicists, leaving aside the debate over the role of bioethicists in the public arena as well as in other domains. However, since in their distinction of the two "theories" of bioethical expertise, they take into consideration not just the debate over the role of bioethicist in the clinical domain, but the entire debate over the topic of bioethical expertise, I consider this distinction as valuable and valid when applied to my primary focus of interest, which is public bioethics.

could be easily solved and even avoided if the parties agree on the meaning of the concepts they are talking about (Beauchamp 1982). This observation rests on the recurrent idea according to which what we often interpret as a moral dilemma (*i.e.* dilemmas regarding moral choices caused by conflicting and mutually incompatible values) is instead bound to semantic and interpretative reasons. Following this reasoning, disambiguating the terms is the preliminary strategy towards the solution of moral dilemmas (Beauchamp 1982)[19]. On the other hand, before defining the main concepts involved in the topics under discussion, an often underestimated preliminary step is in fact crucial: the identification of the problems that deserve some attention. As some scholars have indeed pointed out, problem-solving and concept definition are just secondary tasks of the bioethical enterprise, since sometimes the problem lies in the lack of a clear definition of what are the problems that actually require a solution (Caplan 1989).

Opposed to the narrow theory of bioethical expertise, some philosophers have proposed what has been subsequently defined as the broad theory of bioethical expertise (Crosthwaite 1995; Weinstein 1994). This theory states that, in virtue of their more competent and informed justificatory abilities, bioethicists should be assigned a problem-solving role in cases of moral dilemmas and disagreements. There are two interpretations of this theory, a radical one and a moderate one. According to the less radical version of this theory, the justificatory abilities of the bioethicists are superior to those of laypeople because the former are usually more refined, thanks to their frequent exercise and to their knowledge of moral concepts and theories. However, this does not mean that experts' judgments are infallible, but just that they are more likely to be less fallible than those of non bioethicists (Crosthwaite 1995). The more radical version of this argument argues instead that bioethical expertise is nothing but the normative reflection that primarily includes the capacity of providing strong justifications for a claim in a specific domain.

[19] Even if at a completely different level, the same observation has been put forth by some theorists of the deliberative democracy ideal. They claim that the disambiguating activity is one of the grounding reasons why deliberative approaches to democracy should be preferred to aggregative approaches. For a deepen analysis of this topic see Gutmann and Thomson (2004).

Precisely the emphasis on the strength of the justifications rather than on the consistency between the premises and the following consequences shows what this second version assumes and cannot avoid: the appeal to moral objectivity. According to the supporters of this last view, bioethical expertise is hence possible if and only if there are objective moral truths, which in turn might be considered guarantors of the distinction between justified and unjustified arguments (Weinstein 1994).

4.3.2 Philosophers vs. non-philosophers? Who is more competent as a bioethical expert?

In addition, another controversial question dominating contemporary literature concerning this topic is whether philosophers (and, particularly, moral philosophers) represent the best qualified people to be moral experts, or whether some other professional figures might be better equipped. There are three answers to this question. First of all, there are those who completely reject the idea that bioethical experts should be professionals with a philosophical background, the so-called "argument from common sense morality", originally formulated by Archard (2011) (see section 3.2, *The knowledge-shared argument: shared content between experts and non-experts*). Second, there are others claiming that, given the aforementioned skills and knowledge, there is no doubt that moral thinkers (*e.g.* professional philosophers) are the best equipped to be bioethical experts (Vogelstein 2015). Finally, we find those who support an in-between position and argue that, even if there are no specific competences that philosophers, *qua* bioethical experts possess and that non philosophers cannot acquire, philosophers can fulfil this role better because of clear and contingent reasons, for instance the fact that philosophers receive general training in understanding formal reasoning and a specific competence in moral theories (Singer 1972, 1982, 1988).

5. Conclusions and future steps

This first chapter aimed at providing the reader with a taxonomy of the very complex (and not always systematic) philosophical debate on bioethical expertise. As I showed in

the first part of this chapter, there are several objections to both the existence of bioethical expertise and the legitimacy of bioethical experts. However, several counterarguments to those objections have also been discussed, so that one can still claim that both bioethical expertise and bioethical experts can legitimately exist, provided they are appropriately conceived. In particular, as to the question "where does the expertise of bioethical experts, if any, lie?", there appears to be some knowledge and skills almost unanimously attributed to the content of bioethical expertise, the so-defined "standard argument". As I will show in the third chapter, a slightly modified version of the standard argument will be formulated here. This version aims to combine the already considered elements of the standard argument with some features typically characterizing the public bioethics' domain. However, the main focus will shift from the centrality of coherence amongst judgments to coherence amongst *reasonable positions* – where the validity of the latter is no longer bound to the coherence amongst the overall agent's moral judgments or the coherence between the agent's moral judgment and an alleged moral truth, but to the fact of being potentially justifiable *through mutually acceptable reasons*. The way in which this last expression will be interpreted here refers to its definition in political theories of deliberative democracy.

With regards to the question "what should be the role granted to bioethical experts?" I will defend the view that public bioethicists should be conceived as *ethical experts*, but not as moral experts. This distinction, which I will fully explain in the course of the dissertation, means, in brief, that bioethical experts possess some specific knowledge and skills, but that these skills and knowledge do not legitimize them to take decisions in place of others. Following this distinction, I will argue that bioethical experts can surely be considered as *conceptualizers* of moral issues, but not as problem solvers, thus siding in favour of the so-defined narrow theory of bioethical expertise. In addition to the narrow account, I will also claim that, even if bioethical experts are not entitled to decide and

choose for others, they can nonetheless help others to do this, that is, they can *facilitate* this process.

Finally, following some considerations already pointed out by Peter Singer (Singer 1972, 1982, 1988), I will defend the view according to which, for some contingent reasons, philosophers are best equipped to be bioethical experts.

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CHAPTER TWO

Rethinking bioethical expertise in the public

1. Introduction: from bioethical expertise as such to bioethical expertise within the public sphere

In the previous chapter it has been shown that the issue of bioethical expertise, far from being univocally and systematically structured, is instead characterized by the overlap of different research questions as well as different practical domains, which make the investigation of this topic highly controversial. In order to deal with such a complexity, my strategy will be to narrow the focus of the investigation by establishing the kind of questions I would like to address, and the specific setting in which the type of bioethical expert I am interested in operates. This explains why the purpose of the present analysis is to frame the figure of bioethical expert in the so-called *public arena*. Such a particular domain of investigation clearly establishes the type of questions I am going to address and the type of analysis I will adopt. Indeed, since the focus of this work is bioethics in its public domain, the level of inquiry will be set on the previously defined *political questions on bioethical expertise*: i.e. those questions examining the actual role bioethical experts fulfil in our societies so as to restrict or expand it according to the principles of liberal democracy. To put it differently, in this work I want to propose a role for the bioethical expert within the public sphere, that can be, differently from that stated by most literature, compatible with the tenets of Western liberal-democracies.

Thus, from a methodological point of view, in order to reach such an aim it is necessary to shift the focus of the investigation from the traditional debate over bioethical expertise to the domain of public decision-making democratically characterized. The reason lying behind this choice is that proceeding according to the contemporary debate on the issue of

bioethical expertise does not appear very useful for the analysis of a specific professional figure empirically integrated in a political and social context. On the contrary, it is necessary to set a different and more suitable level of inquiry, meaning the investigation of the conditions under which a public democratic decision-making process might be considered as legitimate, and, accordingly, to further develop the figure of bioethical expert. To put it differently, far from inferring the public mandate of the expert from theoretical speculations, my analytic strategy is to 'reverse the direction' and to infer what the role of the bioethical expert is by looking at those values the expert is demanded to preserve and promote within a democratic society. In order to do this, a further step appears necessary: building a bridge between two different disciplines – namely political philosophy and political science on the one hand, and public bioethics on the other – to improve the latter with some widely recognized and established tools of the former. Indeed, as will be shown in the following sections, the categories I make use of in order to empower the public sphere when dealing with bioethically sensitive issues, far from originally belonging to the discipline of bioethics appear instead widely developed within the two different but communicating traditions of political theory and political science.

This chapter is structured as follows: first of all I will explore the most common public decision-making models (§2) – aggregation (§2.1) and deliberation (§2.2) – so as to ascertain which one can be considered more legitimate for public bioethics. Secondly, I will present some attempts to interpret public bioethics as a specific way of implementing deliberative democratic ideals (§3). Then, I will narrow the focus of investigation by presenting some more concrete ways in which deliberation has been implemented – the so-defined *mini-publics* – so as to present the scenario in which our facilitator might operate (§4).

2. Public decision-making: aggregation *versus* deliberation

2.1 Aggregative decision-making: models and weaknesses

Political theorists of different schools of thought would be willing to recognize at least two alternative models of public decision-making in case of mutually-binding decisions: the *aggregative model* of public decision-making and the *deliberative model* of public decision-making.

The aggregative model of public decision-making has traditionally appeared in two different variants. According to the first one, the way to legitimately cope with moral disagreement and to make nonetheless a decision is to aggregate, *i.e.* to sum, all the expressed preferences of all the individuals involved in the decision, and to proceed with majority voting in order to arrive at the final choice. According to the second variant of the aggregative-based account of public decision-making, the final choice will be the result of a process of public bargaining and negotiation amongst those who take part into the process, thus leading to a choice that is the compromise amongst participants' expressed preferences.

Despite their differences, the two aggregative models of public decision-making share a very important aspect, which might be interpreted, at the same time, also as a sign of their weakness: the idea that the preferences of those who take part in the decision-making process are given *a priori* and that the public arena is just the (metaphorical or non metaphorical) place in which these preferences are expressed and possibly implemented. To put it differently, the idea lying behind this fist model of public decision-making is that citizens' preferences are *not* the *result* of the process of public debate in a public environment, but they are formed long *before* their exposure to the public debate. The so-called public arena would be, then, no more than the place in which citizens express their preferences in order to find a way through which they can be eventually practically implemented.

In addition to this first feature, which constitutes a weakness of this collective decisional methodology, aggregation broadly considered presents also a second fragility. In fact, even if it were true that the preferences citizens express through electoral mechanisms (i.e., through an aggregative method) were their real preferences and, therefore, what results from aggregation really expresses citizens' will, in reality what seems to deserve attention is the *process of formation* of citizens' preferences that precedes their elaborations and expressions. In John Dewey's words, "Majority rule is as foolish as its critics charge it with being. But it is never *merely* majority rule" (Dewey 1927, 207-208). The reason for this is that, according to him, the "counting of heads compels prior recourse to methods of *discussion, consultation and persuasion*" (Dewey 1927, 207-208 – *italics added*). The consequence is that if public decision-making, in order to be democratic, cannot avoid appealing to citizens' preferences, and if aggregation proves just able to collect these preferences but not to have a real impact on them, the remedy is not just to refine and improve already existing methods of aggregative decision-making, but to look for *alternative methods*, more likely to have some influence on them (Dewey 1927; Knight and Johnson 1994).

A recurrent justification in favour of what just said can be found within the so called *social choice theory* (henceforth SCT), which was pioneered in the 18th century by Nicolas de Condorcet and Jean-Charles de Borda, and then took off in the 20th century with the works of Kenneth Arrow, Amartya Sen, and Duncan Black. The SCT can be defined as the study of *collective decision processes* and procedures. This means that it investigates the way through which *individual inputs* of various kinds (for example, preferences and votes) can be aggregated in *collective outputs* (such as, collective decisions) (List 2013). The importance of SCT for my research question lies in the identification of some fundamental weaknesses of aggregative models of decision-making, which have been pointed out precisely by some of the founders of the SCT. Amongst the formers, I will recall the "Arrow's impossibility theorem" – aimed at debunking the system of preferences'

aggregation in general – and the "Condorcet's paradox" – specifically focused on the majority voting and its limitations. In his *Social Choice and Individual Values* (1951), Arrow proved that, once we establish a set of basic criteria or axioms (defined by Arrow as "social welfare functions[20]") aimed at preventing a decision-making process from being arbitrary, we surprisingly find that there exists no method for aggregating the preferences which demonstrates to be able to fulfil these criteria and, therefore, no aggregative method able to escape from the slippery slope of arbitrariness. An example of collective decision-making procedure that is unable to satisfy all the requirements for non-arbitrariness is, according to Arrow, majority voting. This latter was precisely the subject of the analysis of Condorcet's masterpiece: *Essay on the Application of the Analysis to the Probability of Majority Decisions* (1785). Through the analysis of the voting system based on a majoritarian rule, he formulated the famous paradox, according to which the *aggregation* of preferences through majority voting can get to *irrational* outcomes, even when *individual* preferences are *rational*. What rational and irrational mean here can be understood through the appeal to the category of *transitivity*. Reconsidered in the light of this expression, the paradox formulated by Condorcet might be rephrased by saying that even if each voter's preferences ordering is transitive, the majority ordering may not be transitive (Pacuit 2015). The most common way of presenting this paradox is: there are three voters; the first one prefers alternative *x* to *y* and *z*; the second one prefers alternative *y* to *z* and *x*; and the third voter prefers alternative *z* to *x* and *y*; so there are majorities for *x* and against *y*, for *y* and against *z*, and for *z* against *x*, which clearly violates a principle of *transitivity* (List 2013). The lesson that can be drawn from Condorcet is, therefore, that majority rule is at once a plausible method of collective decision-making and yet subject to some surprising problems (List 2013). To sum up, in addition to the potential discrepancy between citizens' expressed preferences and real preferences, which *per se* constitutes a

[20] The social welfare functions individuated by Arrow are the followings: i) unrestricted domain (or universality); ii) non-dictatorship; iii) independence of irrelevant alternatives; iv) positive association of social and individual values (or monotonicity); v) non-imposition (Arrow 1951).

fundamental weakness of aggregative-based models of decision-making, what Condorcet and Arrow have taught us is that another *exogenous* reason exists which suggests why public decision-making cannot be based only on aggregation. That is, aggregation in general and majority voting in particular do not prove to be a reliable measurement of citizens' preferences.

The conclusion according to which aggregation presents inherent limitations can be reached also through another strategy, that is, by appealing to *endogenous* reasons. These can be interpreted in a twofold manner. On the one hand, it might be argued that aggregative models of decision-making are less legitimate than its rivals or, symmetrically, that there are other forms of decision-making models more legitimate than aggregation itself. On the other hand, it may be shown that the conception of legitimacy aggregative models are based on – consistency between social outcomes and popular will – might be better fulfilled by other models of decision-making. Both these strategies will be pursued in what follows. In order do to this, being deliberation the most important rival theory with respect to aggregation, I will start by presenting deliberative-based models of decision-making (and how they differ from aggregative-based model of decision making) so as to show firstly to what extent deliberation is a more legitimate model of public decision-making and, secondly, why and how the conception of legitimacy endorsed by the supporters of aggregation is in reality better fulfilled within a deliberative-based view.

2.2 Going beyond aggregation: deliberative-based models of decision-making

Unlike aggregative models, the deliberative model of public decision-making considers a decision as legitimate when the latter is the result of a process of public deliberation. The meaning of the expression "deliberation" within this context cannot be bound to a single theory. However, far from appealing to this term in its general characterization, I will explicitly acknowledge the meaning it possesses within the so-called theory of deliberative democracy and, in particular, within the elaboration that has undergone in the works of

Amy Gutmann and Dennis Thompson (Gutmann and Thompson 1996; Gutmann and Thompson 2004). The best definition of deliberative democracy so conceived is presented at the very beginning of their masterpiece of 2004, *Why Deliberative Democracy*. In the authors' words: "Most fundamentally, deliberative democracy affirms *the need to justify decisions* made by citizens and their representatives. Both are expected to justify the laws they would impose on one another. […] Its first and most important characteristic, then, is its *reason-giving requirement*. The reasons that deliberative democracy asks citizens and their representatives to give should appeal to principles that *individuals who are trying to find fair terms of cooperation cannot reasonably reject*. The reasons are neither merely procedural ("because the majority favours the war") nor purely substantive ("because the war promotes the national interest or world peace"). They are reasons that should be accepted *by free and equal persons seeking fair terms of cooperation*" (Gutmann and Thompson 2004, 3 – *italics added*).

Rephrasing and explaining what just reported, deliberative democracy should be conceived as that democratic decision-making process according to which representatives and citizens' viewpoints can be presented in the public arena only as long as they can be supported by reasonable justifications (Gutmann and Thomson 1996, 2004). Therefore, as Gutmann and Thompson explicitly argue, the most relevant characterizing feature of deliberative democracy is the so-called reason-giving, where "giving reasons" means providing justifications for the actions, behaviours, and viewpoints proposed and eventually endorsed. Since the effects of publicly made decisions will fall not just upon the single citizen (or representative) making the choice, but upon all the citizens (and representatives) bound by the same choice, we are asked to justify the decisions in a way that is at least publicly comprehensible and sustainable. The second part of the quote goes more in depth and explains under what conditions a judgment might be considered as rationally justified. The definition of rational justification endorsed here somehow appeals to an idea of *reciprocity*, according to which a position is justified in a rational way when it

is bound to principles that free and equal individuals who are trying to find fair terms of cooperation cannot reasonably reject (Gutmann and Thomson 1996 and 2004). This apparently simple expression conveys two fundamental features of the deliberative democratic ideal. On the one hand, it defines the criterion for which a viewpoint can be *presented* (*not accepted*) within the public arena. This does not deal, as it might be thought, with the content of the viewpoint, but with *the way in which* the same viewpoint is *expressed*. Deliberation, in this sense, clearly appears as the decisional process that makes use of *rational argumentation* as the unique legitimate way for presenting and defending positions within the public sphere. In reality, the emphasis put on the level of the justification does not totally exclude the importance of the content from the deliberative domain. Indeed, the idea according to which a viewpoint in order to be legitimately put forth should be acceptable for free and equal individuals, *per se* excludes some irrational, extreme, dominant and unfair positions[21]. In addition to the reason-giving requirement, other criteria have been set by the theorists of deliberation for the definition of a reason as justified. First of all, the reasons provided must be *accessible*, that is, both transparent and comprehensible. This is the so-called "accessibility requirement" (Gutmann and Thompson 2004, 5). More in details, there is a twofold way in which reasons can be accessible: both from a procedural standpoint and from a substantial one. According to the former, the act of providing citizens with reasons (therefore, deliberation itself) must take place *in the public* and not only in the privacy of one's mind, whereas the latter recalls a principle of clarity observing that a deliberative justification does not even get started if those to whom it is addressed cannot understand its essential contents. The last two requirements concern the duration of the validity of the decisions taken through deliberation. These are the "binding requirement" (Gutmann and Thompson 2004, 5) – according to which the need to

[21] A possible way of explaining what defines a position as unjustified within a deliberative democratic account is to recall John Rawls' *The Idea of Public Reason Revised*, which clearly inspired deliberative democratic criterion of *reasonableness*: "Central to the idea of public reason is that it neither criticizes nor attacks any comprehensive doctrine, religious or nonreligious, *except insofar as that doctrine is incompatible with the essentials of public reason and a democratic polity. The basic requirement is that a reasonable doctrine accepts a constitutional democratic regime and its companion idea of legitimate law*" (Rawls 1997, 766 – *italics added*).

maintain political stability requires to consider decisions resulting from deliberation as binding for a period of time. There is also the "dynamism of the process" (Gutmann and Thompson 2004, 6), according to which decisions must also be open to provisionality, that is, to the possibility of being challenged and eventually replaced in the future in case they do not appear valid anymore[22].

However, the 'rhetoric' of reason-giving recognized by both supporters and opponents of deliberative democracy, has not prevented deliberation from being accused of both imperfection and value-leadenness. Indeed, on the one hand, although deliberation is primarily conceived as a decision-making model, deliberative theorists neither specify a unique procedure to reach decisions, nor exclude the need to appeal to a combined model (deliberation regarding reason-giving but majority rule for the final outcome) for reaching conclusive decisions. On the other hand, differently from aggregative models that are clearly neutral, deliberation might be criticized for its value-laden nature. This criticism can be put forth since deliberation reveals, in its endorsement, its grounding on some substantial principles (such as reciprocity, transparency, accountability), as well as on some fundamental assumptions (such as the fact of privileging a reason-based rather than an emotionally-based approach). As long as these two aspects are concerned, aggregation presents indisputable advantages. First of all, it allows the production of determinate outcomes, at least in principle. Secondly, it appears more reliable than its deliberative counterpart in addressing moral disagreement, since the procedures it makes use of are relatively uncontroversial. Finally, making use, most of the times, of a majority rule, the decisions that are reached through aggregation can be considered expressions of the views of the majority of the population.

[22] Provisionality is one of the main strengths of deliberative democracy. This is due to two main reasons, recognized also by deliberative democratic theorists. First of all, human decision-making process and human understanding are imperfect and, therefore, we cannot be completely sure that what is considered right today will be correct also tomorrow. Moreover, in politics most decisions are not consensual, meaning that they might encounter the ideas of most, but not all citizens. Therefore, the fact of being not irreversible could make them more acceptable also to the latter.

However, even if this reasoning might provide additional elements for problematizing the pros and cons of public decision-making models, perhaps turning out in a never ending process, in what follows I will report and properly explain the two endogenous and exogenous reasons that allow to definitely tip the balance in favour of deliberative based models of decision-making.

2.3 Tipping the balance: endogenous and exogenous reasons in favour of deliberation

From the very beginning, the core-distinguishing feature of deliberative approaches of decision-making with respect to the older aggregative ones was a particular interpretation of the so-called 'preferences'. Indeed, far from considering the preferences as already given, seeking only to combine them in ways that are both practically efficient and theoretically fair, the specific aspect characterizing deliberation was the fact of considering the preferences as those *refined* opinions and beliefs resulting from the deliberative process itself. In other words, according to the supporters of the deliberative ideal, before deliberation has taken place, we can speak only of *undetermined* opinions and beliefs, which can aim at becoming real preferences only through the process of discussion and reason-giving, and it is precisely from the latters that the decision-making process must begin. Although this might, and has, be interpreted as a mere terminological and/or factual difference between the two approaches, the thesis that I endorse here is, instead, that it is precisely the definition of preferences as *the product* of deliberation which leads to the consideration of deliberation as a more legitimate decision-making model for the public sphere. However, since this is not the central topic of this dissertation, I will not explore in depth the issue of deliberation's political legitimacy over aggregation, but I will limit to present some widely shared reasons in support of this claim. First of all, by refusing to take for granted expressed preferences as a given starting point for decision-making, deliberation seems able to partially challenge the existing distribution of power in society that, within an aggregative view, would be accepted and even reinforced (Gutmann and

Thompson 2004, 43). Secondly, since deliberation specifies only the criterion for presenting personal viewpoints and contesting others' viewpoints within the public sphere (what has been defined as reason-giving), but it does not provide citizens with a unique methodology for dealing with these preferences, it allows citizens to be active actors in the decision-making process. By contrast, this does not happen in the case of aggregative models of decision-making since, being these concerned with the sum the expressed preferences, they prevent citizens with the chance of challenging their methodologies (Gutmann and Thompson 2004, 10). Finally, and most importantly, deliberation has been considered, by many, not only as a methodology for reaching decisions but also as a *learning process*, able to empower the general population in its public dimension (Fung 2003; Fishkin and Luskin 2005). Put it differently, although reason-giving is obviously a process much more complex than the mere aggregation of preferences because it requires several investments in terms of effort, time, and money (citizens should be informed, should be trained so as to adopt an argumentative way of reasoning, etc.), the leading persuasion widely shared by the supporters of the deliberative ideal is that the public sphere resulting from several processes of deliberation will surely appear improved, that is, more aware and respectful of the plurality of societal viewpoints. This observation does not exclude, *per se*, the consideration of deliberation as the unique decision-making method, but it claims that, even in the case in which deliberation would not be able to allow consensus-reaching and, therefore, aggregation is needed, the preferences that will be then aggregated will be more refined and considered than the ones we could have had if deliberation has not been carried out before. This concept might be defined as 'the possible transformation of opinion and beliefs'. According to it, even if citizens will not change their opinions in the course of deliberation, the preferences resulting from this process will be in any case more informed, more reflexive, and better expressed compared to the ones that might have resulted from their simple aggregation (Gutmann and Thomson 2004, 13-14).

In addition to the aforementioned reasons, there is a final consideration that plays a crucial role within this context, helping to tip the balance definitely in favour of deliberation. This is that, even if we were persuaded that the account of legitimacy proposed by the supporters of aggregation were superior to the one supported by deliberative democrats, the former appears nevertheless better fulfilled through a deliberative approach rather than through an aggregative approach. More in details, the aggregative model of public decision-making found its justification in its conviction of considering itself the best tool to realize popular will. However, what Condorcet and Arrow, among others, have shown is precisely that aggregation in general and majority voting in particular do not prove to be reliable measurements of citizens' preferences and, therefore, cannot be considered as the most proper tools in order to realize popular will. By contrast, the same does not seem equally valid for deliberation. Indeed, once accepted that the preferences resulting from deliberation are what people actually desire, the equal consideration granted by deliberation to any reasonable position, gets the deliberative model of decision-making much more close to fulfil the aggregative conception of legitimacy than aggregation itself.

3. Deliberative democracy and public bioethics

Even if deliberation does not *a priori* exclude other forms of decision-making such as aggregation, the assumption lying behind this research project is that the former constitutes the most legitimate decision-making model in case of mutually-binding decisions of public interest. In this section I will proceed a step further, by narrowing the focus of investigation and focusing on that subdomain of the public sphere devoted to the discussion of the ethical issues: the so-called *public bioethics*. Public bioethics can be defined as the whole range of bodies and procedures such as national ethics councils, parliamentary ethics commissions or public consultations on 'ethical issues' that are meant to inform and guide political decision making with respect to ethical considerations (Kelly 2003; Moore 2012). In particular, it will be argued that the domain in which deliberation

reveals itself as a particularly appropriate model of decision-making is not much 'the public' generally conceived, but public bioethics' domain[23].

3.1 Deliberative democracy as 'the handmaiden of bioethics'

In a seminal paper of 1997, Gutmann and Thompson identify one of, or the main, *raison d'être* for the birth of bioethics: addressing moral disagreement within the public sphere. In the authors' words: "In some sense, bioethics was built on *conflicts*. Abortion, physician-assisted suicide, patients' demand for autonomy all are staple and contentious issues. And the controversies continue to proliferate" (Gutmann and Thompson 1997, 38 – *italics added*).

Gutmann and Thompson are implicitly endorsing one amongst the most recurrent interpretations of what bioethics is: i.e. bioethics as a form of *applied ethics* (Jonsen 1998, Veatch 2003, Hedgecoe 2004, Kuhse and Singer 2006). According to this interpretation, bioethics can be defined as a peculiar kind of ethical reflection that applies principles and reasonings belonging to the domain of normative ethics to contingent controversial ethical issues – i.e. conflicts – with the very final aim to provide a solution to them. Leaving aside the exploration of what should count as normative ethics within this explanatory model, what matters here is the importance granted to bioethical debate to bottom up reasons, namely conflicts and/or dilemmas, at the origin of bioethics' enterprise.

[23] Actually some scholars (Moore 2010; Rei and Yeh 2009) have proposed a reverse position according to which public bioethics might be considered as an exemplary case for practically embedding the deliberative democratic ideals. Rephrasing it through the expression I introduced before, this would mean considering public bioethics 'as the handmaiden of deliberative democracy'. In particular, these scholars have pointed out some more complex explanations that suggest a possible interpretation of some public contemporary bioethics bodies – such as the Nuffield Council on Bioethics (NCB) and the Human Fertilisation and Embriology Authority (HFEA) – as devoted to some extent to deliberation. This interpretation lies on the one had in the fact that public bioethics explicitly draws on deliberative democratic ideals (Moreno 1995, Trotter 2006, Moore 2010b) and, on the other hand, in the observation according to which public bioethics offers a paradigmatic case in order to reflect upon the goals and methodologies of deliberative democracy in some areas intrinsically characterized by "scientific uncertainty, value conflict and high pressure for decisions and regulation, because of the novel ways in which it addresses problems of expert domination and the question of social consensus" (Moore 2010b, p. 715). In other words, public bioethics might be reinterpreted as embedding deliberative democratic ideals, as long as it is conceived as the articulation and representation of a wide range of ethical positions in the public arena (Moore 2010b, p. 723).

Few lines above, they present what they consider as the best tool available to bioethics for addressing such a disagreement: "What forum best serves such debates? A look at political theories of democracy can help answer that question. The most promising for bioethics debates are theories that ask citizens and officials to justify any demands for collective action by giving reasons that can be accepted by those who are bound by the action. This conception has come to be known as deliberative democracy" (Gutmann and Thompson 1997, 38). In other words, deliberative democracy, conceived as a political theory regulating public decision-making, appears, according to its founding proponents, as "the most justifiable conception for dealing with moral disagreement […]" in the public sphere (Gutmann and Thompson 2004, 10). Therefore, once established that the bioethical enterprise owes its origin to moral conflicts, Gutmann and Thompson define deliberation as the most valuable method the former might make use of in order to address and possibly solve the latter. The same reasoning might be expressed in a different manner by claiming that the domain in which deliberation reveals itself as a particularly appropriate model of decision-making is, rather than 'the public' generally conceived, that specific subdomain of the public concerned with bioethical issues, i.e. the sphere of public bioethics.

Moving within this line of reasoning, while seeking to further develop the scope of the justificatory apparatus supporting the framing of deliberative democracy as 'the handmaiden of bioethics', four different argumentations can be additionally pointed out.

The first reason why deliberation appears as the most legitimate model for public bioethics lies in its capacity to promote *the legitimacy of collective decisions*, since it allows anyone taking part in the debate to influence and even to change the outcomes of the final decision, as long as a better argument is provided – thus addressing one of the most relevant sources of moral disagreement, i.e. the scarcity of resources (Gutmann and Thompson 2004, 10). In the authors' words: "The hard choices that public officials and health care professionals make should be more acceptable even to those who receive less

than they deserve if everyone's claim have been considered on their merits, rather than on the basis of the party's bargaining power" (Gutmann and Thompson 1997, 39).

The second reason lies in the fact that deliberation appears as a better tool, as opposed to aggregative methods, to encourage *the development of public-spirited perspectives* on issues of public interest, thus challenging, to some extent, the limited generosity of the individuals entitled to take decisions (Gutmann and Thompson 2004, 10-11). The idea is simple. Very few people are inclined to wholly altruistic behaviours when public policy issues are at stake. Aggregation does not seem geared to intervening into this process, since what it looks for is only a way to take into consideration citizens' interests and not to change citizens' minds and behaviours. By contrast, even if deliberation "will not turn self-centered individuals suddenly into public-spirited citizens" (Gutmann and Thompson 1997, 39), appears better equipped for the task, thanks to its reason-giving process. In other words, the ideal of public arena depicted by aggregative theorists differs profoundly from the one envisaged by deliberative democrats, since the formers aim at realizing outcomes that maximize the preferences of the majority of individuals involved in the decision, whereas the latters aim at ameliorating the behaviour of those habiting the public arena by nudging them to become more altruistic. The same concept has been expressed by John Stuart Mill in the *Considerations on Representative Government*, in which, referring to public discussion (considered here as the equivalent of deliberation), claims that a citizen is "called upon […] to weight interests not his own; to be guided, in case of collective claims, by another rule than his private partialities; to apply, at every turn, principles and maxims which have for their reason of existence the common good" (Mill 1861, 68).

The third reason lies in the fact that deliberation promotes *mutually respectful processes of decision-making*, since it requires the recognition of the merits of viewpoints different from ours, as long as they are equally justifiable (Gutmann and Thompson 2004, 11). The main reason why a decision-making process might be disrespectful is, according to the

supporters of the deliberative ideal, the incompatibility between moral values, which rather than causing an attitude of doubt as to what value should be endorsed, seems instead to get to behaviours of disrespects towards different viewpoints. From an aggregative viewpoint, it seems impossible to overcome such an incompatibility. Indeed, rather then discussing the different viewpoints and values, aggregation takes them for granted. In the face of it, even if deliberation is incapable of making incompatible values compatible, it might, nonetheless, "helps participants recognize *moral merit* in their opponent's claims" (Gutmann and Thompson 1997, 40 – *italics added*). This leads to what Gutmann and Thompson have defined an *economy of moral disagreement*, according to which "by economizing on their disagreements […], citizens manifest mutual respect as they continue to disagree about morally important issues on which they need to reach collective decisions" (Gutmann and Thompson 1997, 40). In reality, it can also be added that, even if deliberation cannot make incompatible values compatible, it might have a substantial role in distinguishing between genuine and superficial incompatibilities and, therefore, between solvable and unsolvable disagreement (Gutmann and Thompson 1997, 40). Indeed, the discussion upon allegedly incompatible views might also lead to the recognition of these views as only *prima facie* incompatible.

Finally, deliberation helps *to correct those mistakes that arise as a consequence of collective decisions*, due to another source of moral disagreement, that is, our incomplete understanding (Gutmann and Thompson 2004, 12; 1997, 40). If bargaining and negotiation might only lead citizens to learn how to obtain what they want (Gutmann and Thompson 1997, 41), it is "through the give and take of arguments" (Gutmann and Thompson 1997, 40) that citizens can learn from each other, recognizing possible collective and individual misrepresentations, eventually expanding their knowledge.

The aforementioned reasons aimed at showing to what extent deliberation might prove able to address moral disagreement in a way that aggregation clearly does not. The massive

importance granted to moral disagreement here has been due to its connection to the birth of bioethics. As Gutmann and Thompson clearly said, bioethics was built upon moral conflict. Precisely this fact together with the reasons why deliberation appears so appropriate in handling moral conflict favours the consideration of deliberation as the best decision-making method for public bioethics.

4. Where does deliberation occur? At the crossroads between experimental political science and public bioethics

4.1 The deliberative opinion poll

What has been shown in the previous sections are the arguments in favour of deliberation as a more legitimate procedure of decision-making, at least in the context of public bioethics. In conjunction with these theoretical observations, deliberation has been proven to have some concrete impacts on citizen's preferences. In other words, even if additional reflections would contest that deliberation is not actually the most legitimate process of decision-making as far as bioethical sensitivity is concerned, what cannot be denied is that it produces some consequences, since citizens' preferences consistently change before and after deliberation (Fishkin and Luskin 2005; Fishkin 2009; List, Luskin, Fishkin & McLean 2013).

The most contemporary and significant example of the consequences of deliberation on citizens' preferences is the so-called Deliberative Opinion Pool (henceforth DOP), originally developed by James Fishkin and Robert Luskin at Stanford University. The DOP consists of a several-steps fixed procedure, whose main features are the following: first of all, participants are randomly and representatively selected from the population and invited to voluntarily participate in a deliberative experiment over a long weekend. Before coming, they receive some concise and carefully balanced materials about the topic that will be debated[24]. In line with what has been stated by the same authors, the arguments present in

[24] It should be noted that all the DOP carried out to date have not addressed bioethical issues, but very different topics that mainly address socio-political decisions. Therefore, the material (as well as the entire

the balanced briefing material contain both empirical premises and purely factual information. This document, which is supposed to provide a starting point for discussion, is in any case checked and approved for its balance and accuracy by an advisory board of stakeholders expert in the specific issue to be debated (Fishkin and Luskin 2005, 288).

Upon arrival, participants are initially surveyed about the issue that will be debated, so as to ascertain their initial preferences. In fact, during what the creators of the DOP have defined as preparatory period – the period from the moment of recruitment to the arrival at the site for deliberation – participants' preferences can be partially altered, therefore influencing the results of the first survey. This happens because, being aware of the fact that they will be part of an important and visible event, they tend to discuss the general issue on which the DOP will be focused with their families, friends, colleagues, and to follow closely the stories the media might present regarding this issue (Fishkin and Luskin 2005, 289). Moreover, the mere fact of possessing the informative material in advance can result in some of them exploring the issue through online or library research before attending the event. However, according to the authors, two sets of reasons prevent the preparatory period from being really problematic, biasing the first survey: firstly, the interaction that occurs during this period is socially homogeneous – since people tend to talk with their peers, the effects of this interaction cannot be equal to the ones that a real socially mixed situation (like the one occurring in the *in locu* deliberation) can allow. Secondly, sociological studies have shown that people tend to turn to sources of information and conversational partners they already agree with, therefore unconsciously looking for those situations in which disagreement with respect to their own ideas cannot be so strong (Fishkin and Luskin 2005, 289).

Once they arrive at the site of deliberation and the aforementioned preliminary questionnaire has been filled in, they are randomly assigned to small groups (about 15

discussion) is built around "the major arguments for and against policy proposals prominent in elite-level discussion" (Fishkin and Luskin 2005, 288).

people each) in which they are asked to deliberate while being monitored by moderators. Moderators, within the DOP account, are figures whose main task is to "maintain an atmosphere of civility and mutual respect, encourage the diffident, restrain the loquacious, and ensure that all the major proposals and all the major arguments for and against them in the briefing document get aired" (Fishkin and Luskin 2005, 288). Thus the role of moderators within DOP is to protect and promote the value of political equality and neutrality.

Deliberative sessions alternate with plenary sessions, in which experts can provide some clarification, if and when necessary. Since the questions that can arise might regard not only factual considerations but also broader issues such as costs and consequences of policy alternatives and the trade-off that might arise, experts should be unbiased in their perspectives.

At the end of the weekend, participants fill in for the last time the same questionnaire as before so that the final preferences of the same participants can be evaluated. As Fishkin puts it, "the resulting survey offers a representation of the considered judgments of the public – the views the entire country would come to if it had the same experience" (Fishkin 1991, 53).

4.2 Deliberative mini-publics

Deliberative-based experiments like the DOP have increasingly grown in number in the last few years, becoming widely popular (Karpowitz and Mansbridge 2005; Karpowitz, Mendelberg and Shaker 2012; MacKenzie and Warren 2012; Himmelroos and Christensen 2013). These are commonly known in the literature under the expression of "mini-publics"[25] (Fung 2003). Mini-publics originated from the ideal of creating more perfect instances of the real public sphere[26]. The results are artefactual self-consciously organized

[25] Actually, the same Fung declares of having taken this term from Robert Dahl's notion of minipopulos (1989) and Jack Nagel's notion of Deliberative Assemblies on a Random Basis – DARBs (1992).
[26] As pointed out by the same Fung, the conditions for deliberation within mini-publics differs from the ones potentially present in the real public sphere in three main respects: inclusivity, attention to rationality, and

deliberative sessions, in which common citizens (in a number that represents only a little portion of the entire population) convene and discuss predefined issues. Despite being small efforts with respect to large-scale public sphere reforms, according to their creators, mini-publics appear very promising because they seem to be the most valid actual mean able to promote civic engagement and public deliberation in contemporary politics. Moreover, precisely because of their size, they are much more able to proliferate and to influence, even indirectly, the public sphere (Fung 2003, 339). Mini-publics have been categorized using several variables which constitute the possible institutional design choices one should go through before setting up a mini-public. In particular, mini-publics are constituted on the basis of the type of participants selected and recruited, the choice of the subject debated, the "deliberative mode" (i.e. the organisation and style of discussion that are adopted within the deliberative sessions), the choice of how much time the deliberation should take and how it should be organized, (i.e. whether the deliberative session is a one-off event or whether it consists of several occurrences). However, what really characterizes mini-publics in their different formulations is the *type* of mini-public one decides to set up, which, in turn, is defined on the basis of the public sphere ideal that one would like to achieve. Archon Fung has identified four different types of mini-publics: i) as educative forums, ii) as participatory advisory panels; iii) as participatory problem-solving collaboration; and iv) as participatory democratic governance. If the last two kinds of mini-publics are specifically aimed at establishing a solid bridge between the state and

information. Concerning the first aspect – *inclusivity* – deliberation in actual debates might be, for some reasons, rather unequal, since those who will be included in actual public debates will surely be wealthier, more educated, in a superior powerful position, granted with higher communicative and rhetoric skills, than the general population. In contrast, what mini-publics try to do is to artificially create those conditions able to include all the diverse voices. Concerning the second aspect – *attention to rationality* – the emphasis put by those who theorize and organize mini-publics on the importance of rationality and reasons might presumably lead to a higher attention, by participants, to others' positions and arguments. In other words, whereas in the real public arena it is unlikely that citizens take seriously others' positions and arguments, in the artificial setting created by mini-publics, participants' behaviours and attitudes appear more serious and focused. Finally, concerning the third aspect – *information* – it exists a very huge difference between the role that is granted to information in the real public sphere and in mini-publics. Indeed, since for some reasons (time, education, will, and so on) the acquiring of information might appear as a costly process, citizens often form only ill-considered opinions. In contrast, the provision of participants with fair and balanced information as a necessary and unavoidable step of mini-publics, lead to discussions and debates that are, in any case, on average superior than the ones occurring in the public sphere. For a deepen discussion on it see Fung 2003, 340-341.

the public sphere, either in order to solve specific collective problems (iii), or to directly incorporate citizens' voices into the determination of policy agendas (iv), the first and the second subcategory of mini-publics have much more an advisory role. Indeed, when it is conceived as an educative forum, the main purpose of the mini-public is to create those conditions that allow citizens to better form, articulate, and refine their preferences on a specific issue of public concern, through a process of mutual exchange; whereas when it is deemed as a participatory advisory panel, the aim is to further develop the preferences of participants and to create those conditions that should enable citizens' considered opinions to be reflected into social choices (Fung 2003, 340-342).

As mentioned before, the DOP constitutes a specific kind of mini-public. In particular it has been considered as a particular type of educative forum. Despite being a specific kind of mini-public with its inherent limitations, the DOP does have some additional advantages. In particular, being designed so as to be representative, the DOP is able to overcome one of the main controversial features of mini-publics: the *participation bias* (Fung 2003, 347), according to which those who participate in deliberative experiments (and experiments generally speaking) are disproportionate with respect to the general population for some demographic characteristics (gender, age, education, profession, health, and so on). Moreover, the fact of providing participants with some balanced and approved informational material as well as with the chance of asking questions to panels of experts ensures high deliberative standards. On the other hand, as with the majority of mini-publics, the DOP presents also some disadvantages with respect to the impact it might produce. In particular, three main reasons prevent the DOP from producing relevant impacts. First of all, participants appear to have very low motivation, that is, they have no real reason to invest their mental energy and resources in deliberation, since the main issues on which the DOP are focused are something that only indirectly affect citizens' lives (Fung 2003, 345). Secondly, being a one-off event (Fung 2003, 354), the deliberation is also unlikely to substantially influence citizens' dispositions. Indeed, mini-publics have

proved that they work as "schools of democracy" (Fung 2003, 350), maximising the chances of cooperation and self-understanding when presenting recurrent deliberations. This might constitute a problem for DOP that are one-off events. However, the fact that the core intervention of the DOP lasts for a long weekend can partially minimize this problem. Finally, since the DOP is not well connected to the levers of state power and decision-making, it has a very low potential to influence institutional affairs (Fung 2003, 354-355).

5. Conclusions

This chapter has been devoted to the presentation and subsequent discussion of decision-making models in the public arena. In particular, starting from the presentation of the two most relevant models of public-decision making, *aggregation* and *deliberation*, I argued that deliberation does not only seem a privilege methodology for public decision-making in general, but that it revealed itself particularly relevant for the subdomain of public bioethics, due to its capacity of handling moral conflict, which is at the basis of bioethical reflection. The second part of the chapter was instead devoted to the presentation of mini-publics as possible ways of implementing deliberative democratic ideals in the practice. The final aim of this exploration was to depict and define the public space in which the normative figure of bioethical expert that will be presented in the next chapter might operate.

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CHAPTER THREE

The facilitator: the normative proposal

1. Introduction

Most deliberative mini-publics, as already shown with the DOP, envisage a role for the moderator in the flow of the discussion. This figure appears in the literature under several different expressions not always well theoretically specified, amongst which the most important ones are 'moderator' and 'facilitator'. In this work, 'moderator' will refer to the figure as generally described in the literature, whereas the term 'facilitator' will be used in order to identify the specific type of moderator whose role will be presented and defended[27].

This chapter is structured as follows: first of all, I will present the reasons bound to the lack of visibility of the moderator within the literature. This means to address both the way in which the theoretical and the empirical debate is structured (§2.1) and the paradoxical features that the moderator (as the figure mediating the debate within the DOP) is asked to fulfil (§2.2). Second, I will provide a review of the theoretical role and functions ascribed to the moderators within the literature (§2.3). Third, the results of the empirical investigations of the moderator's role, as reported within the political science literature, will be presented (§2.4). The second part of this chapter is instead focused on the presentation of a normative proposal: that is the rethinking of bioethical expert as the facilitator of deliberation. In particular, after explaining to what extent the facilitator is asked to possess not only a procedural but also a substantial expertise (§3.2), the main roles, tasks and values ascribed by us to the facilitator are shown (§3.3). The last part of the chapter focuses on the philosophical justification lying behind such a proposal (§4).

[27] As will be explained, in the literature the terms moderator and facilitator are used interchangeably. However, I will follow the distinction explained in the text, in order to avoid possible misunderstandings.

2. The deliberative moderator

2.1 Moderators: why nobody gives them importance

Independently from their specific definition and function, what moderators actually do, within mini-publics and deliberative sessions akin to DOP settings, significantly varies with respect to the deliberative setting in which the experiment is carried out (Fulwider 2005; Farrar *et al.* 2009; Park 2012; Spada and Vreeland 2013), as well as to the specific way in which different scholars interpret their functions (Gerber 2011, 8). Even though there is much debate concerning the proper way of structuring mini-publics, the real influence that the role and functions of moderators have on public discourse and policy decision, as well as on the internal quality of deliberation, is in any case insufficiently theorized. As Alfred Moore suggests, even if this figure is almost always present within mini-publics, their specific role and the values they promote are absent from deliberative and bioethics literature (Moore 2012). One possible explanation for this lack of attention has been hypothesized by Moore himself, who claims that such a phenomenon could be, at least, partially ascribed to the fact that the debate has for a long time been concerned with the theoretical investigation of deliberative democracy as a potentially legitimate account of political authority, rather than with the empirical investigation of the possible institutional implementations of such an ideal (Moore 2012,148). Accordingly, it clearly follows that the issue on which the debate has been focused on, was not the moderator, since the investigation of deliberative democracy, in its various formulation as a more legitimate account of political authority than traditional aggregative forms of democracy, was considered of greater importance.

In conjunction with this preliminary explanation (which nonetheless highlights the overestimation, within this debate, of the theoretical reasoning with respect to the applied one), two additional observations might be added, one pertaining more deliberative theory, whereas the other is more connected to a deliberative practice. First of all, since deliberative theory has been concerned with the ideal conditions of deliberation and not

with their practical realization, the theorization and development of a figure whose task would be to help to realize these ideal features, did not appear necessary. On the other hand, those who pursued an empirical investigation of deliberative democracy have been mainly concerned with the *effects* rather than with the process of deliberation. Moreover, since the moderator might be considered both part of the structure and of the design of the deliberative forum, its investigation has received, also in this latter context, very little attention[28].

2.2 Moderators: some paradoxical features

Along with the theoretical and empirical tendencies, within the debate, to partially ignore one of the fundamental figures of the deliberative setting, there are some additional reasons lying behind this phenomenon. In particular, some scholars (Levine *et al.* 2005; Moore 2012) have pointed out that the mere presence of someone who moderates the discussion can be considered *per se* as a paradox.

First of all, following Moore, the moderator has a twofold role, because this figure can be defined, at the same time, both as part of the structure of the deliberative design and as a participant amongst other participants. Therefore, when conceived as part of the experimental design, the moderator should be as neutral and non-directive[29] as possible, avoiding the influence on the outcome of deliberation. Yet, the mere fact of being a

[28] Actually some attempts aimed at exploring the figure and role of the moderator from an empirical standpoint have already been made, whereas the theoretical study of this figure is almost absent, as pointed out by Moore. For the empirical investigation of the facilitator see: Fulwider, J. 2005. "Do Moderators Matter? Answering a Jury Deliberation Challenge to Deliberative Democracy". Paper prepared at the *Annual Meeting of the American Political Science Association*. Washington, DC, September 1–4, 2005; Farrar, C., Green, D. P., Green, J. E., Nickerson, D., and Shewfelt, S. 2009. "Does Discussion Group Composition Affect Policy Preferences? Results from Three Randomized Experiments". *Political Psychology* 30/4, 615-647; Park, J. Y. 2012. "Testing Conditional Effects of a Moderator in Deliberation: A Lab Experiment". Paper prepared for the annual meeting of the *American Political Science Association*, New Orleans, LA; Spada, P. and Vreeland, J.R. 2013. "Who Moderates the Moderators? The Effect of Non-neutral Moderators in Deliberative Decision Making". *Journal of Public Deliberation* 9.2:3; Gerber, M., 2011. "Who are the voices of Europe? Evidence from a pan-European deliberative poll". Presented at the *ECPR General Conference*, Reykjavik, 25–27 August.

[29] The expressions 'non directiveness' and 'non domination' will be used in order to define some essential features of the moderator that are going to be endorsed in the following paragraphs. Alternative expressions are however present in the literature. For example, Loeber *et al.* have described this concept in terms of the tension between 'responsiveness' and 'leadership' (Loeber *et al.* 2012, p. 2; see also Loeber 2003, pp. 78–79).

participant cannot prevent him/her from intervening somehow in the debate (Moore 2012, 149).

This first paradox leads to a second controversial feature surrounding the figure of the moderator. According to an ideal account, deliberation would require absence of coercion, repression and inequality. On the contrary, what happens in a real deliberative setting is that, since deliberation does not spontaneously and autonomously arise, some figures, the moderators, should intervene and manage the deliberative process in order to make it possible. In other words, the conception of deliberation endorsed by deliberative theorists is highly idealized since it would require a spontaneous origin and self-reinforcement, whereas the experience derived from minipublics clearly shows that, precisely in order to maintain such an ordered deliberation in its ideal characterizing conditions, some degrees of coercion, put in place by trained moderators, cannot be avoided.

Finally, as Simon Thompson and Paul Hoggett have suggested, complex emotional group dynamics arising within mini-publics point to the necessity, for the group, to have in any case someone who leads the discussion. As a consequence, if the moderator acts according to the ideal requirements of deliberation – so as to be non-directive and non-dominant with respect to the other participants – a participant will very likely take a leading position, thus dominating the others. On the other hand, if the moderator exercises a leading position in order to prevent possible forms of domination, the moderator ends up being perceived as excessively dominant and intrusive by the other participants. Through the words of the authors: "a non-interventionist 'hands-off' style can lead to domination by more vocal and confident citizens; a more interventionist, 'hands-on' approach that equalises opportunities for voice may be too domineering" (Thompson and Hoggett 2001, 359).

2.3 Moderators: establishing identity and functions

Once these problematic features, surrounding the figure of the moderator, have been clearly identified, it appears necessary to examine how the moderator is defined within the literature, what the role attributed to such a figure is, and what the values he/she is asked to promote are.

First of all, the same definition of whom the moderator should be, as long as the consideration of what values he/she should promote, does not appear *per se* uncontroversial. Indeed, independently of their role in moderating the discussion, which constitutes a broadly accepted starting point (Forester 1999; Loeber 2003; Mansbridge *et al.* 2006; Smith 2009; Loeber *et al.* 2012; Gerber 2011; Moore 2012), the reasons in favour of the introduction of a moderator into the experimental design of mini-publics vary profoundly. To illustrate the point, Moore considers the moderator as the figure who leads the discussion and interacts with the other participants, in order to achieve the "'internal' deliberative quality within organized deliberations" (Moore 2012, 17), whereas Marlène Gerber connects the definition of the moderator to the role he/she might have with respect to the value of political equality. In her words, moderators are those figures that "should foster balanced participation within the small group discussions and thus make sure that those diverse voices are not only formally present but also substantively expressed in the group discussions" (Gerber 2011, 1). A very similar position is endorsed by Graham Smith, who defines moderators as those figures that, in conjunction with other characterizing design features of minipublics, directly and profoundly affect the fairness of proceedings and equality of voice, thus restrict those who would like to prevail and dominate the group (Smith 2009, 84).

However, irrespective of the main value that the moderator is asked to protect and even promote (either political equality, or internal deliberative quality, just to recall the aforementioned examples), there is a discrepancy in how moderators behave and manage

the small group discussion. A very fundamental difference lies in the distinction between the so-called 'active' and 'passive' moderation/facilitation. Although there is not a unique way of interpreting such a distinction, the same terms intuitively comprise their meanings: in a passive-based moderation/facilitation, the moderator does not properly interact, thus being unable to prevent different group dynamics from happening; by contrast, in an active moderation/facilitation, the moderator promptly interacts with participants and tries to minimize the already mentioned dynamics in order to let the deliberation being adherent to the deliberative democratic ideals as far as possible[30]. Since in a passive-based moderation/facilitation a moderator presents a lesser degree of involvement with participants, the behaviour of moderators thus conceived can be considered homogenous. Diversely, there could be a high variation regarding the way in which active-based moderation/facilitation is carried out. However, since very few people have tried to theorize the behaviour of the moderator, there are no standardized guidelines, but only preliminary indications. An attempt to provide some essential steps as to how to conduct deliberation is the so-called "process talk" theorized by Jennifer Stromer-Galley (2007), according to which what moderators should do during the deliberative sessions is to go through the following steps: first, prompting quiet participants into speaking while curtailing the talkative, asking participants to clarify some possible controversial features, periodically summarizing the discussion, asking whether participants agree or disagree with a specific position, bringing about the discussion of a specific aspect already discussed if necessary and, finally, intervening in case of conflict between participants (Stromer-Galley 2007). As declared by the same author, the *process talk* was elaborated by combining the theoretical literature on deliberation and the empirical literature on small groups, deliberation, online political talk, and conversation analysis (Stromer-Galley

[30] For a theoretical investigation of the distinction between active and passive moderation/facilitation see Smith. He claims that active facilitation proved to have a crucial role in the "shaping and reshaping the conditions for deliberation" in order to "ensuring that marginalized voices are heard" (Smith 2009, pp. 198, 168, 168). For an empirical investigation of the effects of a passive with respect to an active moderation/facilitation see Farrar *et al.* 2009.

2007). Thus it is the result of a complex analysis between both top down and bottom up approaches. A different strategy for developing tools for conducting deliberation is arguably the one first presented by Jane Mansbridge and colleagues (Mansbridge *et al.* 2006). They propose that 'the code of conduct of moderators' could be inferred from the experience of moderators themselves in their consideration of what constitutes a successful deliberation. In particular, they asked ten professional English-speaking Caucasian male moderators to listen to the tapes of ten small group deliberations on public issues from six anonymous organizations in the United States, and to individuate what they considered the good deliberative moments with respect to the less effective ones. This preliminary step aimed to establish the set of implicit and explicit norms adopted by moderators in their personal evaluation of deliberation, which, in turn, should get to the identification of the necessary steps of the moderator's intervention during the deliberative sessions. The norms individuated by the professional facilitators were the followings: i) participants' satisfaction, considered as the capacity of maintaining a positive atmosphere within the group, and ii) group productivity, meant as making progress on the group task (Mansbridge *et al.* 2006). According to Mansbridge and colleagues, in order to satisfy the first requirement (satisfaction as positive atmosphere), which immediately appears potentially damageable by domination, the moderator is supposed to allow and promote free flow (Mansbridge *et al.* 2006, pp. 13-14), whereas in order to satisfy the second requirement (productivity with respect to prior established tasks), the moderator is supposed to provide the group with clear instructions, ensure that the group is properly prepared, keeping the group focused on the task, explicitly explaining the mission of the group prior to the beginning of deliberation and finally writing down statements on which all the people within the group agree (Mansbridge *et al.* 2006, p. 15).

Independently from the different roles and tasks ascribed to the moderator, as well as the values promoted by going through these procedural norms, there is a final decisive controversial issue surrounding the figure of the moderator: this concerns the relationship

between moderation and expertise, i.e. what kind of expertise should be granted to moderators, whether purely procedural or also substantial (Moore 2012, Chlivers 2008). Being the topic of this dissertation, this issue will be explored in depth in the following paragraphs, where a specific type of moderator, the facilitator, will be presented.

2.4 Moderators: preliminary results from empirical investigations

Although a systematic exploration of the figure of the moderator from a theoretical and normative standpoint is largely absent in the literature, some attempts have nevertheless been made in order to investigate the *effects* of its introduction within the deliberative process with respect to the *outcome* of deliberation itself. The very first empirical investigations aimed at putting some commonly accepted assumptions discrediting the usefulness of the moderator to the test (Fulwider 2005). The precedent for this analysis can be referred back to Levine and colleagues, who claimed that, although the widespread reputation ascribed to moderators is that of neutral professional figures able to help participants to work through a fair agenda, they cannot finally be fully democratic and deliberative agents (Levine *et al.* 2005). Indeed, in addition to what Levine has defined the 'positive effects' that the moderators might promote – ensuring high deliberative quality and perception of procedural justice – some negative effects can also be detected, such as suppression of others' ideas that will surely end up restricting individual autonomy. A few years before Peter Levine's work, Devine, while referring to a quite different context (juries rather than mini-publics), argued that within juries, in which the final aim is to reach a decision, the moderator appeared to have the first and the last word in the group (Devine 2001). Starting from these considerations, John Fulwider (2005) empirically investigated the effects that small group moderators could have had on the deliberative outcomes. In particular, he concluded that there could have been two ways in which moderators can somehow provoke harmful effects on deliberation, thus biasing its outcome. On the one hand, by avoiding the occurrence of the normal dynamics which regulate group compositions in real life, participants might have felt dissatisfied with the

outcomes of deliberation, seeing them as fictional outcomes. On the other hand, moderators could also subvert the deliberative process, if they influenced the course of the discussion in a fashion that limited individuals' ability to choose freely among alternatives. The results of this analysis showed that the presence of a moderator increased the perception that relevant points were raised during deliberation, as well as a change in opinions, yet it had neither significant effects on knowledge gains, nor on the perception of fairness (Fulwider 2005).

However, contrasting results were obtained through the experiments carried out by Cecilia Farrar and colleagues, whose general aim was still the investigation of the effects of moderators in small group discussions, but with respect to two different moderation styles, one more active, and one more passive. In the active setting, moderators emphasized the importance of promoting involvement by all participants, whereas in the passive one they did not intervene in the discussion at all. Although impartial observers presided over the two settings in order to be sure that the two different experimental scenarios were fully respected, they did not see statistically significant differences either in the transformation of preferences, or in the perceived legitimacy (Farrar *et al.* 2009).

Finally, some scholars, persuaded by the potential manipulative effects of the moderators, set up studies akin to DOP in order to empirically investigate precisely this aspect. Yu Jeon Park was the first to set up a lab experiment in order to test whether and how much the perceived expertise of the moderators affects the outcomes of deliberation. The alleged irrelevance of this research question can be easily debunked, once it is seen that the majority of moderators turn out to be government officials who might be paid by companies or government to manipulate deliberation (Park 2012). Starting from this empirical question, Paolo Spada and James Raymond Vreeland performed a controlled field experiment in order to explore whether moderators could have really behaved in a neutral way or should have been considered as somehow having a kind of impact over participants' decisions. In order to do so, they hypothesized that, alongside traditional

biasing effects – in this case disruptive effects of inequality, biasing effects of outside influences and polarizing effects of group dynamics – moderators themselves could have biased the outcomes of deliberation (Spada and Vreeland 2013). Results from Park's analysis are that participants proved to be more susceptible to moderators' influence when they perceived the moderator as having some expertise on the policy issue debated. Along the same lines, Spada and Vreeland discovered that when moderators intervened in favour of one option over another, they could have had a significant impact on participants' preferences. By contrast, the presence of a strict rule of discussion favoured the transformation of the preferences towards the less popular option, thus protecting minority positions (Spada and Vreeland 2013).

3. The normative proposal: bioethical expert as the facilitator of deliberation

3.1 Preamble: from political theory and political science to public bioethics

What has been done so far is to provide the reader with a broad picture of the current debate on the role of the moderator. As explained, this figure has rarely deserved a central place in the literature, mainly because it does not seem to fully belong either to a purely theoretical framework or to an empirical kind of sensitivity. Indeed, on the one hand, far from belonging to the ideal conditions of deliberation, which contribute to making deliberation a legitimate form of political authority, the moderator pertains precisely to those non-ideal conditions that can nevertheless make a deliberation actually feasible. On the other hand, if considered in the light of the empirical investigation, the moderator appears to be part of the statistical design of deliberative-based experiments, rather than of the effects of deliberation, which nevertheless constitute the privileged locus of interest within the debate. In any case, as already shown, few exceptions exist on the side of the empirical exploration, where the role of the moderator has been preliminary observed and studied.

However, the analysis carried out so far has intentionally left aside a very central feature which can no longer be omitted: that is, that the overall debate has not arisen within the

field of bioethics but, rather, within the fields of political philosophy and political sciences. In particular, political philosophers have mainly dealt with the theoretical investigation of deliberation as a legitimate account for political authority, whereas the empirical exploration of concrete deliberative settings (such as mini-publics) have pertained and still pertain to the domain of political scientists.

What has just been asserted concerning the deliberation in general similarly appears valid for the figure of the moderator. As the wide literature on mini-publics in its different instances seems to suggest, the deliberative setting in which the moderator operates is built upon issues and topics that have much more to do with the public and political sphere than with bioethics reasoning. Starting from these considerations, the current proposal is to improve the already existing socio-political figure of the moderator so as to make it appropriate within our favoured domain of interest: *public bioethics*. In order not to misleadingly overlap the role that the moderator has within the political domain with respect to the one it could have within the bioethics context, the specific kind of moderator that is going to be presented will be here defined as *facilitator of deliberation*. Far from being reduced to a mere terminological difference, the facilitator differentiates from the moderator for a series of functions and tasks, which, in turn, reflect the endorsement of a specific set of values that, according to this work, should foster public debate and decision-making concerning bioethical issues of public interest. For my purposes, the facilitator is precisely what I consider as the bioethical expert in the case of sensitive issues in public bioethics[31].

[31] Although the normative model that will be presented in details in the present chapter has been specifically devised for bioethics in its public dimension, the same if partially modified seems to be valid also with respect to other bioethical domains. More in details, the idea that the bioethicist might be somehow conceived as a facilitator might also sound applicable for the context of clinical ethics. Even if in this setting public deliberations do not appear as the privilege 'interactional model', we might nonetheless think about decisional processes (broadly speaking) and conceive the bioethical expert in this setting precisely as the figure who moderates these processes.

3.2 The facilitator of deliberation: procedural or substantial expertise?

Before going into the details of this new figure, it is important to make some preliminary clarifications regarding the moderator with respect to the central topic of this dissertation: the issue of expertise. Defining the bioethical expert as the facilitator of deliberation means first and foremost establishing whether the kind of expertise the bioethicist possesses within the domain of public deliberation on bioethical issues is only a procedural or also a substantive expertise. Being a procedural moderator would mean possessing some methodical and disciplined skills that appear necessary in order to moderate the discussion. By contrast, being a substantial moderator would require, in addition to procedural skills, the possession of some *substantive knowledge* in the topic around which the same deliberation is built. The proposal that I would like to put forward is that the facilitator, far from being uniquely a procedural expert, is also a *substantial* expert, meaning that he/she should possess some knowledge regarding the bioethical matters under discussion. More specifically, I hold that a good facilitator is someone who possesses a competence not only in the procedural skills of the deliberative processes – good interactional skills, ability to manage the mostly occurring group dynamics etc. –, but also a substantive knowledge in the issue (broadly considered) that is debated.

Depending on the way in which the substantiality of the facilitator is interpreted, this claim is open to debate. At a first level of analysis this could be interpreted as saying that, being involved in deliberations with bioethics as the privilege object of analysis, the facilitator possesses some knowledge in the discipline of bioethics, in particular with respect to bioethical theories, topics and arguments, which can allow him/her to analyse and manage the bioethical issue and its complexity, more than the other participants. According to this first interpretational layer, the kind of information the facilitator possesses is superior than the one possessed by the other participants, since he/she is not only an expert in the process of deliberation, but also in the *content* discussed. Obviously, if this is how the expertise of the facilitator is interpreted, it can easily follow that if a

participant possesses both the bioethical knowledge required to discuss the topic at stake and the procedural skills to handle the process of deliberation, he/she can ideally be considered as a potential facilitator. Another consequence would follow from the acceptance of this statement with respect to the debate introduced in the first chapter of this work: "who is more entitled to be a bioethical expert?'" (Chlivers 2008, Archard 2011, Moore 2012): if we accept what has just been said, it clearly follows that, even if there are no strictly necessary reasons for considering the facilitator as a bioethicist professionally speaking, there are nevertheless some contingent reasons in favour of the latter. Indeed, as shown in the first chapter, even if we could hypothesize that there are some people able to manage the discipline of bioethics and its contents in a proper way (even better than bioethicists themselves), it would nevertheless appear intuitively clear that bioethicists are most probably those that, thanks to time and training, ultimately appear more suitable for this role (Singer 1972, 1982, 1988).

There is also a second way in which the substantial expertise of the facilitator can be interpreted: the facilitator could be defined as a bioethical expert because of his/her *epistemic authority*. If this is true, we should ascribe a powerful role to the facilitator, due to the fact that he/she appears to possess not only a deeper substantive knowledge of the issues at stake, but also a greater authority on how to solve (and not just to carry out) the deliberative process. In other words, the facilitator should be considered as having a privileged role thanks to his/her superior expertise in handling moral facts, from which, in turn, a higher authority to take ethical decisions then follows. This more robust claim can be analysed from very different perspectives. One possible way would be in the light of the *metaethical* stance of the bioethical expert. However, since this is far from being the scope of this dissertation, I will not enter into this debate. By contrast, I will limit to making a brief consideration from the side of public bioethics. Deliberative democracy being considered here as the most legitimate form of political authority for public bioethics, a clear consideration can be pointed out with respect to this second interpretational layer. In

particular, if the democratic component of deliberative democracy requires that any decision influencing the life of a person should be taken also by that person, it follows that the decisional authority is split here between all the subjects involved in the decision itself. In other words, the democratic component of deliberative democracy (which is assumed here as the most legitimate form of political authority for public bioethics) prevents from ascribing a superior authoritative decisional role to the facilitator, precisely because it considers all the decisional subjects as granted with the same authority.

3.3 The facilitator of deliberation: roles, tasks and values

According to this new account, the bioethical expert, as the facilitator of deliberation, should fulfil three main tasks, implementing some central values of democracy: *enhancing individual autonomy* and *public-spirited perspectives*, on the one hand, and *mediation*, on the other one (see **Figure 1**).

By enhancing autonomy, the facilitator promotes some values, amongst which the most important ones are *comprehension*, *self-reflection*, *critical thinking* and *critical reasoning*. In fulfilling this first role, the bioethical expert should complete the following tasks:

i. Ensuring that all the participants express a preference;

ii. Ensuring that the preference is grounded in commonly accepted scientific information;

iii. Inviting participants to provide logically coherent arguments in terms of justified preferences;

iv. Ensuring that arguments presented are coherent (both in juxtaposition with a subject's other preferences and with different subjects' ones; intra-personal and inter-personal consistency);

v. By analysing participants' expressed preferences, the facilitator helps them to better clarify, expose and develop their ethical position;

vi. Showing the consequences of adopting each position both at an individual level and a societal one.

In the enhancement of public-spirited perspectives, the facilitator promotes some respect-based values, amongst which *pluralism awareness* and *mutual respect* are the most important ones. In fulfilling this second role, the bioethical expert should complete the following tasks:

i. Encouraging participants to interact with each other;

ii. Ensuring that participants adopt a cooperative manner;

iii. Presenting unexplored alternative ethical perspectives in order to show the participants the range of the actual and possible ethical arguments concerning the issue at hand (when necessary);

iv. Maintaining a neutral position: under no circumstances revealing, implicitly or explicitly, his/her own opinions and/or beliefs.

v. Encouraging participants to respect each other's reasonable positions and subsequently ensuring that the position is presented in a way that allows for an argument which can be considered acceptable by those willing to accept fair terms of cooperation.

Finally, by acting as a mediator, the facilitator promotes some cooperative values, amongst which *equal participation*, *non interference* and *non domination*. In fulfilling this third role (i.e. the one the facilitator shares with the moderator, as it appears in the literature), the bioethical expert should act as an arbiter and complete the following tasks:

i. Ensuring that all the participants have the chance to speak, giving them time to think and reflect;

ii. Restricting the talkative, by stopping them when they go over time;

iii. Taking steps to eliminate any possible domination due to the pre-existing asymmetries between participants;

iv. Keeping time;

v. Avoiding providing participants with additional scientific information (apart from that already presented in the supplied material), and with unjustified substantive ethical perspectives that will lead them to consider the facilitator as an authoritative source of knowledge;

vi. Manifesting a non-directive behaviour towards any ethical position that he/she considers the best.

4. The facilitator of deliberation: where does philosophical justification lye?

4.1 Why (democratic) deliberation

Once a very brief picture of the role of the facilitator of deliberation is provided, it is clearly necessary to establish what the justifications are in favour of its introduction into the public sphere. There are several assumptions lying behind this proposal.

The very first philosophical justification for the development and introduction of the facilitator of deliberation is that, although there are already some institutions focusing on bioethical issues of public concern (especially in the Anglo-Saxons countries), the role of the bioethical expert in the public arena has not yet been standardized or institutionalized – unlike in clinical or academic settings. However, one might legitimately wonder why public bioethics should require a specific standardised process and, in this specific case, a special kind of management based on the presence of a figure intervening into a process that would otherwise go ahead autonomously, driven by experts and lawmakers. The answer to this question that this work provides is twofold. On the one hand, as already pointed out, it can be said that bioethics in its public dimension deals with issues that will then lead to mutually-binding decisions. This, in turn, according to the democratic system, requires the voice of people to be heard and rightly considered. On the other hand, taken alone, the democratic component does not say anything, *per se*, about the legitimacy of

deliberation. To give an example, as already seen one could act according to a democratic criterion (in the meaning considered here) even by aggregating the expressed preferences of all the subjects involved. By contrast, the conditions of politically legitimate authority cannot be met with the democratic component, but seem to also require the deliberative one. In other words, as largely explained in the second chapter of this dissertation, deliberation constitutes the most legitimate public decision-making procedure. The very final claim made here is therefore that we may fill this void with a new professional figure, specifically devoted to the promotion of deliberative ideals amongst those who are taking the decision and who will bear its consequences.

4.2 Why facilitation

The aforementioned reasonings constitute only a part of the wide variety of reasons supporting deliberative democracy as the most legitimate form of political authority in the sphere of public bioethics. Once these justifying reasons in favour of deliberation are clearly stated and explained, one might wonder why introducing a practice like *facilitation*, which might empower the process of deliberation but also move towards negative uncontrolled outcomes, should be promoted and pursued.

Being the theoretical role of the facilitator almost absent within the literature, also its justification appears underdeveloped. Among the explanations of those who explicitly speak of moderation and/or facilitation, the privilege explanation is that, as deliberation is justified in virtue of its promotion of political equality, the presence of the moderator/facilitator is justified since he/she appears as the guarantor and the promoter in the practice of this ideal (Fishkin and Luskin 2005; Gerber 2015).

Although this can be considered as the justification lying behind the third role fulfilled by the facilitator (i.e. when acting as a mediator), the overall justification for the introduction of the facilitator cannot be reduced to its connection with political equality. Far from limiting uniquely to this perspective, here I defend the view according to which

the philosophical justification for the introduction of the facilitator (within the deliberative process) lies in the role that he/she appears to have in the development and promotion of participants' *considered judgments*.

The precedents for this idea can already be found in some scholars' works which, despite not specifically referring to the figure of the facilitator, nevertheless highlight the importance of balanced and aware opinions within the public sphere. Carolyin M. Hendriks (2006), following John Dryzek (2001), pointed out the importance of exposing deliberators to a maximal diversity of discourses associated with an issue (Hendriks 2006). The consistency between collective decisions and the overall set of discourses present in the public sphere was precisely what the same Dryzek considered as the condition for attaching the label of 'legitimate deliberative procedure' to a deliberation. In the author's words: a deliberative procedure is legitimate "when a collective decision is consistent with the constellation of discourses present in the public sphere, in the degree to which this constellation is subject to the reflective control of competent actors" (Dryzek 2001, 660). A similar position has been endorsed by Susan Dodds and Colin Thomson who, despite speaking of diversity in viewpoints rather than in public discourses, claimed that the role of national bioethics commissions is to expose citizens to a range of different reasonable ethical positions so as to cultivate the development of different viewpoints (Dodds and Thomson 2006). The importance of being exposed to a wide variety of perspectives, being discourses or viewpoints, is also confirmed by some field interviews carried out by Jason Chlivers, who reported that, when asked to establish what deliberation left them in terms of experience, participants considered the exploration of different viewpoints as more valuable than reaching a consensus (Chlivers 2008, 173). Starting from these fundamental pillars, but taking the argument further, I argue that it is precisely the exposure of deliberators to different discourses and viewpoints that can allow the formation and/or development, in the former, of considered judgments.

However, traditionally the merits ascribed to the figure of facilitator here have been actually bound to the same deliberative process that, thanks to some intrinsic characterizing features of the same deliberative design, should appear *per se* able to promote the formation of participants' considered judgments. Amongst these features, the most recurrent in the literature are the exposure to different experts' views, the exposure to different peers' views and, finally, the fact of being designed so as to orient participants towards common goods rather than individual goods (Smith 2009, 94-96). In particular, the exposure to different experts' views is considered here as the means not only able to clarify some previously unclear issues but also to raise issues unknown before. The exposure to different peers' views is supposed to help participants to pay attention to how their peers see and examine their own experiences, so as to have a kind of experience that is more akin to theirs. Finally, thanks to their own design, intentionally devised so as to allow an inclusive and fair deliberation, deliberative-based settings such as mini-publics should prove to be able to orient citizens towards public interests since they are, in turn, grounded in the assumption that only under conditions of political equality would it be possible to make decisions oriented towards the promotion of the public good.

Although all these reasons could appear valid at first glance, there are, nonetheless, some additional observations that can explain why deliberation alone cannot actually allow the formation of considered judgments. These will be shown by taking into consideration precisely the same features pointed out by Smith, and by debunking their validity with respect to their influence over the formation of considered judgments. The first feature ("exposure to different experts' views") can be ideally accepted as valid; however, I believe that the facilitator might better fulfil the role ascribed to experts by Smith. Even if this latter proposal could be perceived by many as dangerous – in the scenario presented here the facilitator is the one who represents the plurality of voices that are usually embedded in a plurality of experts – there are some valid reasons in support of this claim. The most relevant is that the facilitator, thanks to its role, is supposed to show a neutral

behaviour, even in the case in which he/she is the only directing actor. Thus, the facilitator will probably be much more able than normal experts to embed a plurality of perspectives and to grant them an equal consideration. Indeed, if the formers are trained so as to bring to discussion their specialist knowledge and what is mainly valuable according to it, the former is specifically trained in the light of neutrality[32]. Concerning the second feature ("exposure to different peers' views"), even if what stated by Smith is ideally valid, there are some contingent reasons that seem to require the introduction of the facilitator for allowing its effects to be actually observed. The very first reason is that it does not appear necessarily true that all the different viewpoints on a topic emerge during deliberative sessions. Indeed, due to time constraints (deliberative sessions are not endless processes) but also to knowledge constraints (if participants are not experts in the topic/discipline discussed, they are not supposed to know, and will not probably know, whatever should be known on it), not all the perspectives will probably spontaneously arise during the discussion. The second contingent reason is that an exchange of ideas and positions uniquely between peers cannot be necessarily considered as the best means to clarify some unclear positions. Indeed such a claim assumes that deliberators are all experts in the topic and, therefore, possess the correct information to discuss the issue at stake. By contrast, what currently happens in non-facilitated/moderated deliberative setting is that participants try to get the necessary information to discuss from their peers, thus often falling both in reasoning fallacies and in content mistakes. Finally, regarding the third aspect ("orientation of citizens towards public interests"), the assumption lying behind it is that deliberation is both a self-explanatory process – meaning that it is able to self explain its importance to those who participate – and also a spontaneously arising process – meaning that its ideal conditions and values appear as spontaneously implemented in practical settings, without outer interventions. However, both these assumptions are not true *a priori* and, actually,

[32] In any case, in order to prevent from possible abuses by the side of the facilitator, the facilitator's presence is accompanied with the provision of some balanced material on the issue to be debated prepared by experts with different viewpoints on the topic.

seem to require relevant efforts in order to produce the effects they think they will obtain. The introduction of a facilitator seems relevant, also in this third case, in order to help realising the scenarios depicted by both the aforementioned premises. Indeed, on the one hand, the facilitator in his/her second role (as a promoter of public spirited perspectives), by disentangling the controversial nodes of the issue debated, is precisely supposed to show to the deliberators the importance of such an occasion, particularly with respect to the contribution it can have towards the development of a common good. On the other hand, as already seen, even if traditional deliberative theorists such as Habermas have for long time considered deliberation as a so perfect machinery that it would have been able to spontaneously flourish, paradoxically, some akin to constrain mechanisms have to be introduced in order to make it actually functioning in line with its ideal premises (Habermas 1995)[33].

Once what just stated has been clearly understood, one last objection to the necessity of introducing a facilitator within deliberative processes may still be raised. The importance of the facilitator was related here to the influence he/she might have for the development of participants' considered judgments. However, one might wonder what is the justification lying behind considered judgments, that is, why it is so important that participants develop judgments that are considered, and why it cannot be, instead, that participants are left with the possibility to freely decide, whatever the content of the decision is and however such a decision has been obtained. The answer that I would like to provide here is that deliberators are implicitly obliged to adopt a self-critical attitude within the context of public decision-making (in this case public bioethics) since the decisions to be taken will

[33] Actually, the claim that deliberation, according to Habermas, would have been able to spontaneously arise is not altogether fair. Indeed the same Habermas pointed out the importance of protecting the so called "ideal speech situation" through the following norms: (1) Every subject with the competence to speak and act is allowed to take part in the discourse; (2) a) Everyone is allowed to question any assertion whatsoever; b) Everyone is allowed to introduce any assertion whatsoever into the discourse, c) Everyone is allowed to express his attitudes, desires, and needs; (3) No speaker may be prevented, by internal or external coercion, from exercising his rights as laid down in (1) and (2) above. (89). However, the ideal representation of deliberation still remains in Habermasian account, once we consider that, according to him, the mere presence of these norms is considered as the condition for the correct fulfilment of a deliberative process (Habermas, J., 1990. *Moral consciousness and communicative action*. Cambridge, MA: MIT Press).

be mutually binding. In other words, the claim is that the development of considered judgment cannot be considered a supererogatory task in the public sphere, but, rather, a strict obligation, since what follows from public deliberation will directly or indirectly affects the entire population. On the other hand, what has just been said does not seem to be similarly valid in the context of private moral dilemmas, since their resolution primarily affects the subject taking the decision. The dichotomy private/public (and the correspondent one: moral dilemmas/ethical disagreements) might easily recall the concept of 'public reason' of Rawlsian memory, as well as several political philosophies within the tradition of political liberalism. However, in order to better explain to what extent the development of considered judgments should be considered as a strict obligation within the public sphere, while can be viewed as supererogatory in the private one, I will refer to a variation of the "competence principle", the latter having been systematically elaborated by Jason Brennan in 2011. Before looking into its details, it seems noteworthy to start recalling the core ideas conveyed by Brennan, so that the broader setting in which the competence principle is developed might appear clearer. Brennan main claim is the following: "since the governed are forced to comply with the decision of the electorate, negligent decision-making is intolerable" (Brennan 2011, 708). And he adds that, within a system based on majority voting, if the majority "ha[s] imposed a ruler on innocent people without having adequate grounds for the decision", "then majority voters have done something deeply unjust" (Brennan 2011, 708). In other words, Brennan is arguing for political illegitimacy, within non-ideals conditions[34], of universal suffrage. And the basic argument reported here acts as a preliminary justification for it. The idea is simple: since, as a consequence of genuine disagreement, democratic decisions will surely not satisfy all those affected and, therefore, those whose desires have remained unsatisfied, will perceive

[34] As I will explain better below in the text, Brennan explicitly states more than once that he is arguing that moderate epistocracy constitutes the best, in terms of political legitimacy, form of government, but that within the real world this is the less worse one. Through his words: "My goal is limited: all things remaining equal, in contemporary democracies, restricted suffrage would be a moral improvement over unconditional universal suffrage. That said, restricted suffrage might still itself be unjust – better than universal suffrage, but not good enough to qualify as just. Restricted suffrage of might be unjust, but less unjust than unconditional universal suffrage" (2011, 701).

these decisions as enforcements, it seems to exist a duty, by the side of the electorate, to do whatever they can in order to avoid a "negligent decision-making". To what extent a decision-making process can be defined as negligent is explained, by Brennan, on the basis of its proximity and/or distance from the so-called *competence principle*. Although Brennan presents different formulations of the competence principle in relation to the specific domain in which it is embedded, we will refer to a more general definition that proves to work for several circumstances and fields. This states that "when a decision is high stakes and involuntary imposed through force upon others, it must be made by *reasonable* and *competent people* in a *reasonable* and *competent way*" (Brennan 2011, 701 – italics added). As this preliminary definition suggests, the meaning of 'competence' (belonging to the expression 'competence principle') does not limit, within Brennan's account to the possession of knowledge in the specific area in which decisions are taken (in Brennan's case, politics), but include also what he will then define as "moral reasonableness" (Brennan 2011, 701). In another formulation of the competence principle, Brennan indeed claims that "it is unjust to deprive citizens of life, liberty or property, or to alert their life prospects significantly, by force and threats of force as a result of decisions made by incompetent or morally unreasonable deliberative body, or as a result of decisions made in an incompetent and *morally unreasonable way*" (Brennan 2011, 701 – italics added). Few pages after this, what moral reasonableness means is clarified. Here Brennan claims that it does not refer to the possession, by deliberative bodies, of *correct* moral beliefs, but to the way in which decisions should be taken, that is, in a reasonable way, and by reasonable people[35]. Starting from the consideration that both possession of the required knowledge and reasonableness of decision-makers and decision-making processes are necessary conditions to have an active role within the public sphere, Brennan advocates for

[35] The idea of "reasonable people" Brennan has in mind seems to be precisely the one presented by John Rawls in "The Idea of Public Reason Revisited": "Citizens are reasonable when, viewing one another as free and equal in a system of social cooperation over generations, they are prepared to offer one another fair terms of cooperation according to what they consider the most reasonable conception of political justice; and when they agree to act on those terms, even at the cost of their own interests in particular situations, provided that other citizens also accept those terms" (1997, 770).

what he defines as "moderate epistocracy" (Brennan 2011, 701), according to which "a polity is epistocratic to the extent that knowledge and competence are legal requirements for holding political power" (Brennan 2011, 701).

Starting from Brennan's premises but moving beyond them, I argue that a rather different principle should drive public non-experts' interactions. Similarly to Brennan I endorse 'moral reasonableness' as the necessary unavoidable requirement to entering in the public sphere. However, differently from Brennan, I reject 'knowledge-possession' as a precondition for granting the electorate with political power (specifically, some kind of power over bioethical issues) within the public sphere and, as a consequence, moderate epistocracy as the less worse (as Brennan himself has defined it) form of political legitimate authority. The reason for this rejection is twofold. First of all, although the same Brennan claims that his moderate epistocracy should not be conceived as "the most or ideally just form of government" (Brennan 2011, 201), but as the less worse with respect to the already existing ones because of its capacity of being implementable in *actual democracies*, his account nonetheless remains an ideal one. Indeed, even if he claims he is arguing in favour of a *moderate* form of epistocracy, the criterion of competence, meant as full knowledge and moral reasonableness, actually unquestionably and unsurprisingly recalls the kings-philosophers proposed by Plato.

Secondly, even if it were practically implementable, in his distinction between those who are supposed to be entitled with political power and those who are not, he refuses to consider that third layer that is actually constituted by most of the electorate and that, despite not granted with *direct* decisional power, can be, nevertheless, considered to have a legitimate say in public matters. In order to explain it, let me consider the analogy with Wayne Sumner's distinction between moral agents and moral patients, belonging to the moral debate on abortion (Sumner 1981). While explaining the characterizing features that an embryo should possess in order to be considered as a person and, therefore, as morally

valuable, Sumner claims that even if there is surely a huge difference between those who belong and do not belong to the moral domain, some important differences exist also *within* the moral realm, between those who *fully* possess the characteristics for being considered as *moral agents*, and those who just *partially* possess or *no longer* possess these characteristics and, therefore, can be defined only as *moral patients*. Starting from this distinction, I would say that the idea that Brennan has of the electorate resembles Sumner's conception of moral agent – Brennan's electorate should be indeed competent both in terms of being reasonable and possessing the required knowledge to make political choices. This reasoning leads to two main consequences. On the one hand, it discards all those who do not possess these characteristics from (in Brennan's case) the political domain, as not politically worthy. On the other hand it overlaps the figure of the expert (who has to possess these characteristics) with that of average citizen (who, most of the times, is not supposed to possess them), thus falling in an extreme, rather than moderate, epistocracy.

Differently from Brennan, I believe that the electorate broadly considered looks much more like Sumner's moral patients than moral agents and, therefore, that different criteria should be applied. Although I am not willing to give up reasonableness (precisely because of the fact that decisions in the public sphere are mutually-binding), I do not think the possession of strict knowledge can be considered as a valid criterion for inclusiveness. Indeed, first of all a prior issue would arise as to where to set the knowledge's threshold; secondly, it could be claimed that knowledge would appear much more strict if the electorate would be granted with direct decisional power, whereas in the view endorsed here the electorate possess only an advisory power (and therefore an indirect decisional power); finally the fact of knowing something does not entail the more problematic but useful effort of having properly considered it. Precisely because of these reasons, I propose to substitute knowledge-possession with 'consideration', which appears a much broader concept involving both less specialist but more focused knowledge on the issue that will be

subjected to political decision, and the awareness component, obtained through the mutual exchange of perspectives and respective reasons between citizens. Therefore, the justification in favour of the duty (for what Brennan defined as 'the electorate') to develop considered judgments within the public sphere lies in what we shall define "the consideration principle", according to which when a decision is at high stakes and its outcomes are mutually-binding, it must be made through a process of mutual exchange of considered opinions by reasonable people. However, if not further developed, such a principle and the view it conveys would remain as much ideal as in Brennan's view. This is precisely the reason why the figure of the facilitator is introduced. In this view, the facilitator can be considered as guarantor of the consideration principle and, therefore, of the participants' development of considered opinions concerning bioethical issues. The way in which this might be practically realized is explained in the next paragraph.

5. Conclusions: a possible way to implement this figure

Obviously, if we are to use a facilitator in every circumstance we have to take a mutually-binding decision, the process of public consultation will not probably come to an end. The proposal is to make use of this figure only in public debates involving ethical issues and only for *advisory purposes*. In particular, I propose to involve a facilitator every time we need the viewpoint of general population in cases of formulation, implementation and/or revision of already existing or new laws, or simply in situations that cannot be primarily defined as bioethically-centred, but which indirectly rise several ethical issues and concerns[36]. There are indeed several interpretations as to how define the goals of deliberation. Some scholars persuaded of the absolute power of public deliberation might consider it as the most valuable means to reach decisions, whereas others more sceptical

[36] An example of it could be the very recent debate concerning the use of mesenchimal stem cells in the treatment of neuronal diseases widely known as "Stamina Case". For a scientific discussion of the case see the following articles appeared on Nature: "Italian stem-cell trial based on flawed data" (http://www.nature.com/news/italian-stem-cell-trial-based-on-flawed-data-1.13329); "Row over controversial stem-cell procedure flares up again" (http://www.nature.com/news/row-over-controversial-stem-cell-procedure-flares-up-again-1.14613); "Stem cells: Taking a stand against pseudoscience" (http://www.nature.com/news/stem-cells-taking-a-stand-against-pseudoscience-1.15408); "Leaked files slam stem-cell therapy" (http://www.nature.com/news/leaked-files-slam-stem-cell-therapy-1.14472).

about the feasibility of putting in place a deliberative process any time a decision has to be taken might identify in the consultation of the public the only reachable goal of deliberation. What has just been said for the deliberative process could be broadened so as to include the same facilitator. Far from considering the facilitator as a figure that should be implemented within public deliberations any time a decision involving bioethical issues has to be taken, the proposal here conveyed is to rethink the way in which public bioethics is now working, building a mixed institutional setting, both expertocratic and non-expertocratic. The non-expertocratic part of the system would be made up by public deliberation processes empowered with the figure of the facilitator. In particular, public deliberations, according to this view, should take the institutional form of mini-publics and, in particular, should be conceived as *mixed versions* of the first (educative forum) and the second (participatory advisory panel) subtypes of mini-publics. Indeed, even if the aim of this first part of the mechanism is purely advisory, what is obtained through public deliberation should have at least some indirect linkages with the social ethical choices decision-makers are going to make. Given that, it clearly follows that although the primary purpose of this mixed version of mini-public should prompt the formation of participant's considered judgments, the connection to the way in which such judgments could be implemented in real public policies appears also very important. Once the will of the people is clearly established, the final outcome would be passed to the hands of an expertocratic body, being this the same legislative body, or a subgroup of it, working on the bioethical topic, who would work so as to find the most appropriate and feasible way to actually realise it legally.

FIGURE 1

ROLES	TASKS	VALUES PROMOTED
MEANS OF AUTONOMY	i. Ensure that all the participants express a preference; ii. Ensure that the preference is grounded in commonly accepted scientific information; iii. Invite participants to provide logically coherent arguments in terms of justified preferences; iv. Ensure that arguments presented are coherent (both in juxtaposition with a subject's other preferences and with different subjects' ones; intra-personal and inter-personal consistency); v. By analysing participants' expressed preferences, the facilitator helps them to better understand and develop their ethical position; vi. Show the consequences of adopting each position both at an individual level and a societal one.	I. Comprehension II. Self-reflection III. Critical-Thinking IV. Critical Reasoning
ENHANCER OF PUBLIC-SPIRITED PERSPECTIVES	i. Encourage participants to interact with each other; ii. Ensure that participants adopt a cooperative manner; iii. Present unexplored alternative ethical perspectives in order to show the participants the range of the actual and possible ethical arguments concerning the issue at hand (when necessary); iv. Maintain a neutral position: under no circumstances reveal, implicitly or explicitly, his/her own opinions and/or beliefs. v. Encourage participants to respect each others' reasonable positions and subsequently ensure that the position is presented in a way that allows for an argument which can be considered acceptable by those willing to accept fair terms of cooperation.	I. Mutual respect II. Pluralism awareness
MEDIATOR (=MODERATOR)	i. Ensure that all the participants have the chance to speak, giving them time to think and reflect; ii. Restrict the talkative, by stopping them when they go over time; iii. Take steps to eliminate any possible domination due to the pre-existing asymmetries between participants; iv. Keep time; v. Avoid providing participants with additional scientific information (apart from that already presented in the supplied material), and with unjustified substantive ethical perspectives that will lead them to consider the facilitator as an authoritative source of knowledge; vi. Manifest a non-directive behaviour towards any ethical position that he/she considers the best.	I. Equal participation II. Non interference III. Non domination

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CHAPTER FOUR

The facilitator under testing

1. The empirical investigation: does the facilitator have any impact in the transformation of citizens' preferences?

The purpose of this dissertation is not only to redefine the role of the bioethical expert, but also to explore empirically such a normative proposal. In this context, I conceived a lab experiment to verify and challenge the notion that, in the public sphere, bioethical experts can contribute as facilitators to the deliberative decision-making processes.

1.1 Aims of the experiment

The experimental study was conceived in a hypothesis-driven fashion to compare three different deliberative settings (unsupervised, moderated, facilitated), to identify the most suitable condition under which the highest rate of transformation of preferences could be achieved, in particular towards a pluralistic view (see *Study Design*).

In keeping with the main experimental goal, the study was structured into three experimental arms: *unsupervised*, *moderated*, and *facilitated* (see Chapter III). All the participants received some basic scientific information. The same information was provided to all participants in all arms.

- The *unsupervised* setting is conceived as the social space in which participants have the chance to meet in order to properly discuss topics of common interest.

- The *moderated* setting represents the traditional scenario of deliberative experiments. In this setting, group discussion is moderated by an 'arbiter', whose primary function is to act as a timekeeper and as a regulator of group dynamics (Forester 1999; Loeber 2003; Mansbridge *et al.* 2006; Smith 2009; Loeber *et al.* 2012; Gerber 2011; Moore 2012).

- The *facilitated* scenario represents an empowered version of the second one. Here, the main difference is the presence of a proper *facilitator*, whose characteristics have been proposed in the previous paragraph (Paragraph n.4, Chapter III, "The normative proposal: bioethical expert as the facilitator of deliberation"). This setting is grounded on the broader abstract theoretical setting that, in order to have legitimate mutually-binding decisions, it is not enough to have someone who guarantees people a fair chance to express their opinions. Conversely, it is maintained that only by promoting (in a non-directive way) self-reflective attitudes aimed at fully exploring personal viewpoints (which are in turn partly due to the trained exposure to others' perspectives), lay people might actually arrive to legitimate public decisions.

1.2 Preliminary investigations

I implemented two preliminary studies in order to select the topic addressed in the actual deliberative experimentation and also in order to assess the suitability of the target population (university students) sampled for the main study. I wanted to select a topic for which my population had as few preconceptions as possible. I also wanted my sample to be as representative as possible of the Italian population. The results of the two preliminary studies were analysed together in an integrated fashion, as described below.

- In the first study (exp. 1), about 800 undergraduates (belonging to different faculties of the University of Milan) were asked to participate in a pilot study, which consisted of filling in a questionnaire focused on four topics: i) genetic testing in general, ii) genetic testing directed towards consumers, iii) genetic testing related to reproductive choices and iv) Genetic Modified Organisms. For each topic, participants were asked to express their opinions about three moral statements concerning specific questions, by choosing among three possible options "I agree/I do not agree/ I do not have a definitive position on this topic yet".

- In the second study (exp. 2), an Italian demoscopic institute (Doxa) was asked to administer the same questionnaire to a sample of 1000 Italian citizens. Doxa's analysis was performed making use of a CAWI (*Computer Aided Web Interview*) methodology, according to which participants: i) were asked to fill in a questionnaire uploaded on a specific web page; ii) they were asked to fill in the questionnaire alone, without the help of any interviewer; iii) they had the chance to focus on the statements and to reflect upon them. The CAWI methodology presents several advantages. First of all, it reproduces the way in which the questionnaire was later administered in the main experimental setting (for an example of the questions and the distribution of answers, see **Table 1**). Moreover, the system records the time each participant spends filling in the questionnaire. This latter feature helped us in planning the schedule of the main experiment. For the specifics of the demographic sample analysed by Doxa, see **Table 2**.

For the analysis, I first evaluated the percentage of undecided students in exp. 1, who chose (for each question in each topic) the "I do not have a definitive position on this topic yet" (IT: "non ho ancora una posizione definita in merito"). This was done because I wanted to select a topic for the main experiment with as little 'ideological bias' as possible. I assume that this bias is high when we have a high percentage of people with very defined opinions (answers: I agree or I do not agree).

Then, by using the CHI-SQ statistical test, I compared the percentage of undecided students in exp. 1 and in the general Doxa population (exp. 2), and also with the subpopulation of "Doxa Students" (individuals between 18 and 25, with a high school diploma or an academic degree) (See **Table 3**). These tests indicated that in general, the University of Milan (henceforth UNIMI) sample was consistent with results from the Doxa sub-population of students, but not always of the whole Doxa population. However, on two topics (*genetic testing directed towards consumers* and *genetic testing related to*

reproductive choices) the concordance between the student population of exp. 1 and the general population of exp. 3 (Table 3) was acceptable.

All in all, I selected the topic *genetic testing related to reproductive choices* which represented the best compromise between undecided students and congruence with the general population.

Table 1. Example of participants' responses

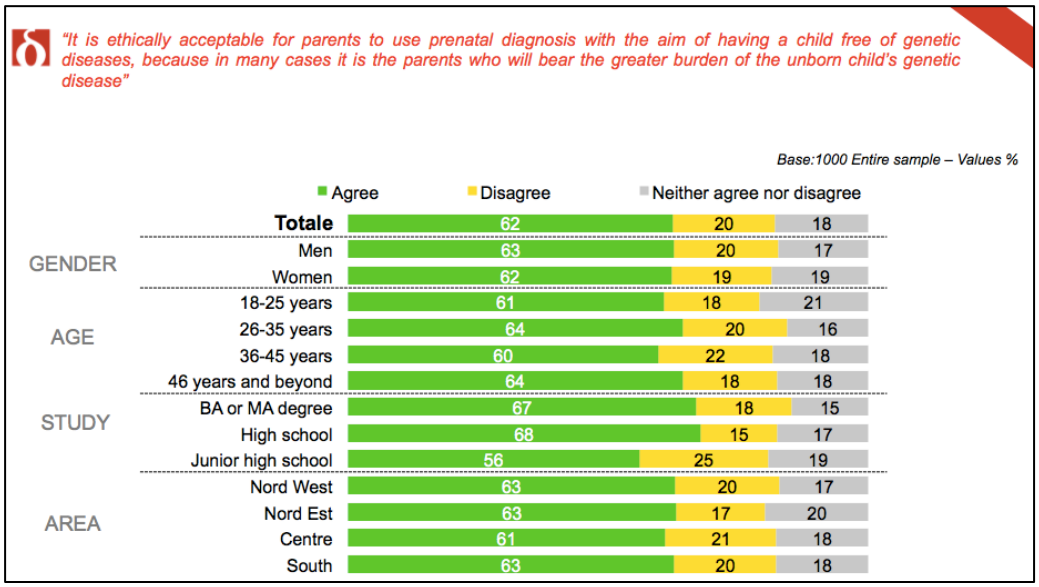

Table 2. Doxa's demographic sample

		Participants
	Total	1.000
GENDER	Men	500
	Women	500
AGE	18-25 years	135
	26-35 years	218
	36-45 years	292
	46-60 years	355
STUDY	BA or MA degree	182
	High school	595
	Junior High School	223
AREA	Nord West	263
	Nord Est	188
	Centre	223
	South	326

Table 3. Choice of experimental subjects and experimental issue

TOPICS	UNIMI Students, Uncertainty rate (%)	Comparison with Doxa Population, Uncertainty rate (Chi-sq)	Comparison with Doxa (Student's subpopulation) Uncertainty rate (Chi-sq)
Genetic Testing: right not to know, duty to inform	33%	309	62
Genetic testing directed towards consumers	19%	95	12
Genetic Testing and Reproductive Choices	29%	120	14
Genetically Modified Organisms	50%	318	95

1.3 Materials and Methods

I designed the trial following as closely as possible the template of a laboratory experiment, in order to grasp the causal effects of my three interventions with good enough internal validity[37]. Two hundred and seventy-four undergraduate students from the first and the second year of different departments of the UNIMI were enrolled. The target population for these studies is anyone who has a say in influencing policy decisions, either directly or indirectly (Park 2012). Obviously, results with a higher degree of generalizability could have been obtained sampling subjects from the general public. However, there are recognized advantages in enrolling students, such as low participation fee and easy recruitment. Furthermore, on the basis of the meta-analysis of 136 studies, Anton Kuhberg has showed that student participants do not display statistically significantly differences when experimenters try to change their attitudes from non-student participants (Kuhberger 1988, Druckman 2001). In order to incentivize students'

[37] Lab experiments constitute an experimental method in political science and they are usually opposed to field experiments. They ensure high internal validity, thus allowing causal inferences; high experimental control over the recruitment, treatment and measurement of subjects and variables and relative economy of the experiment itself. However, they have some disadvantages such as low external validity (and, hence, low generalizability), artificial environment and unrepresentative subject pool (Levitt and List 2007; McDermott 2008; Iyengar 2011). The main reason why I decided to adopt this kind of experimental method in this setting is that it allows more than all the other methods the isolation and testing "of the effects of specific components of certain causal variables" (Iyengar 2011, 75).

participation, they were awarded elective academic credits according to the number of hours they spent in the experiment.

The quantitative analysis of the results deserves some explanations as to the methodology. The primary goal of the lab experiment was to measure the transformations of the participants' preferences towards a pluralistic perspective in the three different settings[38]. A secondary goal of the study was to measure the transformation of preferences altogether. Scholars following the Stanford tradition of the DOP hold that the mere transformation of preferences is a valid indicator of the legitimacy of mutually-binding decisions, since it can be considered as one of the main proofs of the activity of critical thinking and exposure to the perspectives of others. However, the simple modification of preferences cannot constitute a value inasmuch as the transformation is considered equally relevant in any direction: moving from a moderate position to a more conservative one is equivalent to moving from the former to a more liberal position. The guiding idea endorsed here is, instead, to look at the transformation of preferences in a given direction, that is, towards the perspective advocated by deliberative democrats (broadly speaking), more respectful of moral pluralism. We understand this latter as "the fact that a plurality of conflicting reasonable comprehensive doctrines, religious, philosophical, and moral, is the

[38] As it might be easily pointed out, the primary aim of testing the goodness of the facilitator with respect to the promotion this figure operates towards a pluralistic ideal does not seem able to spell out the figure of the facilitator in its broad complexity. In particular, if one compares the taxonomy of the roles, tasks and values of the facilitator in its normative dimension (see Chapter three) with the aims this experiment would like to measure one might easily observe that only two out of three functions of the facilitator are tested. In other words, far from being able to test the figure of the facilitator in its complete taxonomy, the experiment that I performed seems able to have a say only on the second and the third functions of the facilitator, that is, on the facilitator as a promoter of public-spirited perspectives and as a mediator. The reason lying behind the choice of excluding the first role of the facilitator from the empirical analysis (the facilitator as a promoter of autonomy), which might be individuated as the core function within a traditional bioethics framework, is twofold. On the one hand it might be argued that the mere fact of exposing participants to deliberative sessions and to the mutual exchange of moral viewpoints (in addition to the previous provision of participants with informative material), is already a way for promoting participants' autonomy. On the other hand, if autonomy is also conceived, as it happens here, as a way for providing participants with the ability to formulate arguments in a consistent way (with respect to publicly relevant ethical issues), I should have elaborated an additional criterion for evaluating the goodness of participants' reasonings before and after deliberation, which seemed, to me, as an unfeasible option. Precisely the awareness that facilitator was not put under testing in its own entirety seems also to lead towards a reconfiguration of the weight that should be given to the results of the empirical analysis that is going to be explained.

normal result of its culture of free institutions" (Rawls 1997, 766), and of a genuine disagreement concerning what constitutes a right action.

While I herein endorse the idea that measuring the shift of participants' preferences towards a pluralistic perspective is a sounder and more tenable position, I nevertheless elaborated a questionnaire that could also be used to measure the general change of preferences, without particular direction. In this dissertation, I will present the results of the quantitative analysis towards the primary experimental goal (shift of preferences towards the pluralistic view). The computation of the quantitative assessment for the secondary goal is still being performed and will require some time before all the results are computed.

To analyse the questionnaire according to the guiding idea of having a shift of the participants' preferences towards a pluralistic perspective, we assigned a score to each question, assuming that some answers were more in line with a pluralistic perspective than others. We only scored those questions that were directly relevant for our first goal (shifts towards pluralism), leaving aside those included to measure the transformation of the participants' preferences. We did not score those questions for which one (or more) of the following criteria applied: i) the impossibility of interpreting a question in the light of the dichotomy public/private. ii) The fact that the question might have led the participants to endorse implicitly or explicitly, a substantive ethical standpoint (i.e. the thesis of equivalence between foetus and embryo) prevents the analysis to be able to distinguish between those that have provided a specific substantive answer after the evaluation of the fact of pluralism, from those that have provided the same answer without any reference to pluralism. Without further information regarding the reasons lying behind the choice made, it is impossible to understand whether the answer was given in a critical or acritical way, that is, whether participants took into consideration others' perspectives. iii) The fact that the question might have led the participant to endorse other perspectives that do not seem definable in terms of their closeness with a pluralistic standpoint (i.e. the question about

evolution)[39]. Therefore, for the analysis of the participants shift towards pluralism we only considered the following questions: **1**, **3**, **5**, **8**, **9**, **10**, **11**, **12**, **13**, and **14**.

I assigned the scores using a 5-point scale, 5 being the score for the answer closer to a pluralist perspective and 1 being the score for the most distant one. In some cases (questions 7, 13, and 14), I decided to assign the score 5 to two different answers (and then the scores 3, 2, and 1 to the other answers) since, depending on the interpretation provided to the question, two answers could have been considered closer to a pluralistic perspective.

Table 4 shows the scores assigned to each answer for each question:

Table 4. Scores assigned to each question

Question	Strongly disagree	Disagree	Neither agree nor disagree	Agree	Strongly agree
1	1	2	3	4	5
2	1	2	3	4	5
3	5	4	3	2	1
4					
5	1	2	3	4	5
6	5	4	3	2	1
7					
8	1	2	3	5	5
9	5	4	3	2	1
10	5	4	3	2	1
11	4	5	3	2	1
12	5	4	3	2	1
13	5	5	3	2	1
14	5	5	3	2	1

To assign the scores to each answer from the pluralistic perspective, some general guidelines were followed:

1. Ideally a pluralist perspective has its grounding value in the respect of any perspective, even those radically different from own ones, as long as it is based on a principle of reasonableness. For this reason, the fact that some practices count as

[39] Because of these reasons, question **4**, and question **7** have been excluded from the final count. Furthermore, question **2**, and question **6** have also been excluded since their interpretation in the light of the new perspective of analysis might have been controversial. In question **2**, the term "directed" can indeed create some ambiguity as far as the strength of the sentence is concerned; in question **6**, the presence of the terms "acceptable" and "obliged" in the same sentence can make it difficult for participants to orient as far as which of the two terms has the larger scope, and so has to be taken as priority in the interpretation of the sentence itself.

obligatory in the public domain, can potentially be detrimental for the moral equality that is defended from a pluralist standpoint, since it would assign a different moral value to different substantive perspectives. The scores to the questions 1, 3, 9, 10, 11, 12, 13, and 14 have been assigned on the basis of this principle. All the sentences that had to be evaluated in these questions started with "*It is NOT ethically acceptable for parents to use PGD or PD*". Apart from the specific reasons for why each sentence justified the moral unacceptability – reasons that can be more or less valid and reasonable –, pluralism has the goal of maximizing individual freedom. Hence, pluralism is difficult to reconcile with a sentence that limits individual freedom by interpreting the access to PGD or PD as unacceptable. Such a position can be defended only from a substantive moral perspective.

2. The score assigned to question 5 has been attributed on the basis of the fact that a considerable amount of the emotional, psychological, and economic burdens of having an ill child are intuitively borne by the parents. If this is so, it can be hypothesized that answers that allow potential parents to decide freely on their reproductive choices are more respectful of a pluralist sensitivity. In deciding how to evaluate the answers to this question, two aspects that can be particularly problematic have been taken into consideration: the first deals with the burdens that will be borne by the future individual himself/herself; the second with a possible interpretation of "burdens" as limited to the economic kind. As for the former aspect, it is easy to see that, actually, it will be the future individual to bear the major burden of his/her own illness rather than his/her parents. However, the aim of the question was not to analyse all possible moral agents – regardless if actual or potential – that can play a role in this decisions and to establish to whom the greater burden has to be attributed. But rather to consider the actual moral agents that *in fact* find themselves in the situation where they have to decide what to do. These are the agents (and, therefore, the choices) that the public domain cannot ignore. Moreover, it cannot be denied that in the first years of

life and in those cases in which the subject cannot become conscious of his/her own situation, all of the burdens are borne by the parents. Finally, a pluralist standpoint has to be morally neutral also as far as the ontological issue on the status of the foetus or of the embryo is concerned. Since on this issue public disagreement is extreme, the only way to maintain a pluralist perspective is to let the parents decide: they will do that on the basis of their substantive ethical perspectives. Denying them the possibility to choose would be equivalent to imposing a specific substantive perspective. As far as the second issue is concerned, one can claim that other solutions are possible, if the interpretation given to "burden" focus only on the economic kind; for instance, one can claim that the National Health System could or ought to take care of ill subjects bearing the economic burden of their care. Following this interpretation one could disagree with the statement in question 5. However, the interpretation of "burden" as dealing only with economics is limited. Even in the case the parents did not bear the full economic burden of caring for sick children, there are still emotional and psychological costs for the parents.

3. The reasoning behind the assignment of the scores for question 8 can be explained through the analogy with the ethical debate concerning Assisted Reproductive Technologies like the in-vitro fertilisation (henceforth FIVET). A pluralistic standpoint should in principle agree with the use of technology when the goals are those of medicine. For instance, in replying to the objection on the artificiality of FIVET, one can argue that the technological developments in medical care allow today many interventions that could have been analogously considered unnatural and yet are not questioned. Thus, it can be asked to those who consider FIVET unnatural whether the same argument could or should be used in the case of pacemakers, for instance. However, the decision has been to assign the higher score to two answers since one can disagree with the claim that the aims of medicine are actually "*to prevent and to cure disabilities*", even from a pluralist perspective.

4. The reasoning lying behind the assignment of the score for question 11 – taking for granted the rejection of those statements that limit individual liberties (point 1.) – has focused, in particular, on the concept of penetrance and on the fact that one may find fair to limit individual freedom where the penetrance of potential illnesses found is low.

5. The decision for the scores of questions 13 and 14 – taking for granted the rejection of those statements that limit individual liberties (point 1.) – is grounded in the conviction of considering equally valid two answers, since pluralism might have undesirable consequences if all the subjects, being fully free to decide on their own, would orient towards one single direction – that is, if they all decided to avoid producing ill offspring. In a sense, pluralism would become *self-defeating*: it would allow parents to decide freely from constraints in the present, but it would limit the perspectives that would be allowed within the public domain in the future (question 13). Ideally, if all parents orient themselves towards the choice of not producing ill offspring, the voices and needs of those individuals would no more be taken into account in the public domain. Moreover, social rejection towards those ill individuals that might anyway exist in such an idealized world (question 14) – either because not the all the existing genetic pathologies are identifiable by prenatal genetic testing or because some parents may still decide not to counter-select the embryo and/or the foetus – represents an undesirable outcome from a pluralist standpoint.

The aim was, thus, to test whether the three experimental interventions made a difference in the transformations of the participants' preferences towards a more pluralistic perspective. It can be easily objected that some degree of unconscious manipulation by the facilitator might inevitably occur (Park 2012; Spada 2013). Therefore, in order to minimize such an effect, I adopted some specific debiasing precautions. First of all, before starting the experiment, facilitators were asked to fill in the same questionnaire that the participants had to fill, in order to explicitly state their preferences on the topic they would had to work

on. Moreover, facilitators were previously trained in order to follow some preliminary established guidelines, as explained below. Finally, and most importantly, at the end of the experiment, the participants randomized to the facilitator-aided arms were asked to evaluate their facilitators and to declare whether they thought they had been manipulated. In order to reduce the variability originating in the differences between experimenters, some additional precautions were taken. As suggested by Karpowitz and Mendelberg, it is important to find out how experimenters were trained (Karpowitz and Mendelberg 2012). Following this suggestion, the researchers participating in the experiment met three times before the experiment to discuss the details and to simulate the intervention they would have to make. In particular, in the first gathering, the experimenters met in order to discuss the study design and the population targeted; finally, the preliminary schedule of the experiment was discussed. In the second meeting, the details about the three kinds of interventions were discussed, with particular attention to what to say and how to say it, in order to standardise the procedures. In the last meeting, the final schedule was presented to experimenters and a role-play was set up in order to simulate the real experimental setting and to test all the details previously discussed.

The second precaution taken was that experimenters were asked to dress similarly and avoid revealing their academic background.

Finally, when they started their interventions in their sub-groups, all the experimenters were asked to follow these scripts:

Observer:

“My name is X and I will be observing your group as you discuss the ethical issues that can arise from the informative material you have just read. I will not intervene in any way. I cannot provide you with any additional information. You can either start a discussion based on the informative material or based on the questions you found in the questionnaires. I will only tell you when the time for your discussion is over”.

Moderator:

"My name is X and I will be you arbiter today as you discuss the ethical issues that can arise from in the informative material you have just read. I will only intervene so that everyone gets a chance to express his or her opinion. I will keep time of your interventions so that everyone can speak for the same amount of time. I will not provide you with scientific or ethical additional information. You can either start a discussion based on either the informative material or the questions you found in the questionnaires. I suggest that you start by presenting yourselves, your background, and by expressing your preferences on the topic at hand".

Facilitator:

"My name is X and I will facilitate this group today as you discuss the ethical issues that can arise from the informative material you have just read. I will keep time of your intervention, making sure that everyone gets the chance to express his or her opinion. Moreover, I will help you promote an open and respectful discussion on different perspectives on the issue at hand. My role in facilitating this group is that of helping you to elaborate your own position. You are just asked to justify your preferences – that is, provide reasons for them that can be considered acceptable by reasonable people even though they may not share your perspective – I will help you do that. Any reasonable position you will defend will be considered equally valid. I will not judge your position, I will only help you understand and consider various possible implications and consequences of it, nor will I provide you with any scientific additional information. If necessary, I will just refer back to the material you have read. I suggest that you start by presenting yourselves, your background, and by expressing your preferences on the topic at hand".

1.4 Study Design

This study is designed as a randomized controlled trial (see **Figure 5**).

Students have been randomized into three different groups equally distributed (1:1:1) and then, based on the number of students present every day, they have been randomized again into subgroups of 4/5 students each (statistical acceptable range: 4-8). The study was run over 10 days with a total of 60 subgroups (due to several absences in a specific day, and in order to maintain the statistically acceptable range of people, one subgroup was not formed). The study was conducted so as to be a modified version of the standard DOP design[40]. Instead of receiving the materials at home beforehand, participants received the material directly during the experiment (**Appendix 1**). This choice has been made in order to avoid that participants have the time to look for further information or to discuss with others. Providing the informative material in a controlled setting prompts uniformity in the background information that participants can access. Moreover, due to time and costs constraints, the parallel sessions with experts (those alternating with the small deliberative sessions within groups) were eliminated from the study design. All the students filled in an initial questionnaire before randomization in order to evaluate their initial preferences only concerning the bioethical topic under debate (T0) (**Appendix 2**). Apart from the questionnaire, students were asked to provide some personal information, such as: gender, age, and their university department. Participants then received the informative material, consisting of a very simple reconstruction of the scientific aspects of the issue that they would debate later on. This very simple summary aims at providing the students with some very basic information concerning the topic of interest in a balanced way. Students had one hour to read the material; during this time, they were not allowed to interact with each

[40] The reason why I decided not to adopt an exact DOP scheme is due to a weakness of the DOP already debated in the political science literature. Indeed, some scholars criticized the DOP on the basis of a variety of empirical grounds, mainly arguing against the consideration of the DOP as an experiment (Kohut 1996; Merkle 1996, Mitofsky 1996). In particular, they criticized the internal validity of the experiment, by claiming that the lack of a control group made it impossible to know whether any change in individual opinion "is due to the experience of being recruited, flown to Austin, treated like a celebrity by being asked their opinions on national television and having participated in deliberations, or just due to being interviewed twice" (Mitofsky 1996, 4-6).

other or to use other sources of information such as the Internet, mobile phones, or newspapers. At the end of this session students filled in a the second time the same questionnaire that they had filled in upon arrival in order to measure the impact of the information received on their initial preferences (T1) (**Appendix 3**). After the completion of the questionnaire, each subgroup began the deliberative sessions, with three different modalities: the first group discussed the topic without any supervision (Unsupervised group), the second group deliberated with the help of a moderator (Moderated group), and the third group deliberated with the help of a facilitator (Facilitated group). The deliberative session lasted 75 minutes. At the end of the deliberative session all the students were required to fill in for the third time the same questionnaire filled in before in order to evaluate the impact of deliberation (in the three different modalities) on the preferences of the participants (T2) (**Appendix 4**).

Furthermore, I also took into account the participants' perceived legitimacy. In particular, I conducted a qualitative survey in order to assess the participants' perception about two points: first, had their exchange preserved and promoted the values of deliberative democracy; second, how would they rate generally their experience (for the evaluative questions, see the last section of **Appendix 4**).

Finally, approximately 30 days after the end of the study, I asked the participants to fill in the same questionnaire one last time in order to evaluate the long-term effects of deliberation over their preferences (**Appendix 5**). For more specific details concerning the daily schedule and timing of the experiment, see **Table 6**.

1.5 Outcomes

The primary outcome is the mean of individual change towards a pluralist perspective from questionnaire at time T0 and questionnaire at time T2. I have calculated it for each student.

The effect of intervention has been measured as the difference between the Unsupervised, the Moderated, and the Facilitated group respectively (which constituted the intervention groups).

To calculate the minimum mean individual change observable (MIC) I assumed that I would have enrolled at least 100 students for each group. The variance of the population in each group varied between 5 and 100, 80% of power using a two sided and 5% level t-test.

The minimum mean individual change observable (MIC) is between 0.89 and 3.98, when variance of population in each group is 5 and 100 respectively.

Moreover, differences in participants' perceived legitimacy and the correlation between perceived legitimacy and preferences' transformation have been measured.

Figure 5. Study Design

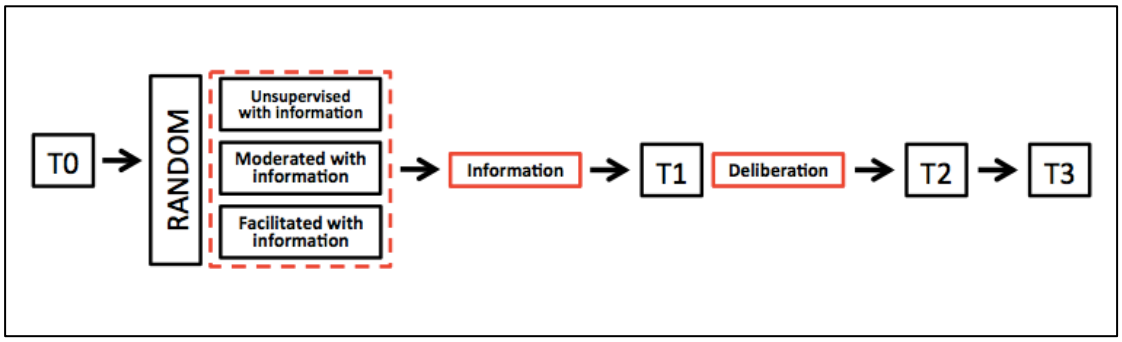

Table 6. Daily schedule of the experiment

TIME	ACTIVITY
8:30 – 9:00	Participants' arrival and registration
9:00 – 9:15	Participants are sent to the conference room where they receive a sealed folder with the materials for the experiment, and a randomized identification number
9:15 – 9:30	Participants read and fill in the informed consent
9:30 – 9:50	Participants fill in the first questionnaire (T0) (**Appendix 2**)
9:50 – 10:50	Participants read the informative material provided (**Appendix 1**)
9:50 – 10:50	Participants and experimenters are randomized into sub-groups
10:50 – 11:10	Participants fill in the second questionnaire (T1) (**Appendix 3**)
11:10 – 11:20	Participants are divided into the sub-groups and assigned to the experimenter that would follow them – as an observer, a moderator, or a facilitator – during the discussion. Each sub-group is sent to a different room in order to avoid contacts between them
11:20 – 12:35	Sub-groups discussion
12:35	Participants return to the conference room
12:40 – 13:00	Participants fill in the third questionnaire (T2) (**Appendix 4**)

2. Results

2.1 Towards a pluralistic public sphere: results

Table 7 shows the characteristics of the participants and the answers to the questions at T0. There is no statistical difference at T0 among the three arms of intervention (all p-values <0,05), with the exception of question 2 where I found a slight difference in the facilitated group as opposed to the unsupervised and the moderated ones, respectively 52%, 25%, and 22% (p=0.023). However, since the difference is present only in one question out of 14, it can be concluded that the randomization was appropriately conducted (**Table 7**).

By analysing the mean individual change between T0 and T1, I observed 44 (16%) students with outliers defined as external to the range median ± 1.5* interquartile range (score≤-6 or score≥6). Being outliers, these students have been excluded. Therefore, I considered 230 students for the primary outcome.

There are no statistically significant differences between the moderated and the facilitated group as well as between the facilitated and the unsupervised one. However, if observed singularly as opposed to the unsupervised group, the data show what follows (**Tables 8-9**):

- The moderated group presents a statistically significant difference with respect to the unsupervised group at T3, as compared to T0. In particular, at T3 the moderated group shows a median difference opposed to T0 of 0.48 (STD:2.35); whereas the unsupervised group it is of -0.37 (STD:2.27) (**Table 8**). These means are statistically different (p=0.0033) (**Table 9**). Therefore, the moderated group is the one that appears to have significantly transformed its preferences from T0 in the direction of a more pluralistic perspective.
- 3.6% of the participants did not provide the correct answer to at least 3 comprehension questions (for the comprehension questions, see **Appendix 3**).

- Data shows that only 10 students out of 274 have not understood the information contained in the material. It can, thus, be concluded that the informative material was appropriate and comprehensible for the sample.

Table 7. Participants' characteristics and answers to questions in T0

Variable	All N (% col)	Unsupervised N (%row)	Moderated N (%row)	Facilitated N (%row)	P
Degree					0.621
Philosophy	64 (23.4)	19 (29.7)	26 (40.6)	19 (29.7)	
Physiotherapy	58 (21.2)	20 (34.5)	21 (36.2)	17 (29.3)	
Medicine	104 (38)	32 (30.8)	31 (29.8)	41 (39.4)	
Cognitive Sciences	1 (0.4)	1 (100)	0 (0)	0 (0)	
Nursing	39 (14.2)	16 (41)	10 (25.6)	13 (33.3)	
Radiology	8 (2.9)	2 (25)	4 (50)	2 (25)	
Age					0.266
<21	124 (45.3)	47 (37.9)	38 (30.6)	39 (31.5)	
>=21	150 (54.7)	43 (28.7)	54 (36)	53 (35.3)	
Gender					0.952
F	152 (55.5)	51 (33.6)	51 (33.6)	50 (32.9)	
M	122 (44.5)	39 (32)	41 (33.6)	42 (34.4)	
Question 1					0.364
Does not answer	1 (0.4)	0 (0)	0 (0)	1 (100)	
Strongly agree	162 (59.1)	53 (32.7)	54 (33.3)	55 (34)	
Agree	76 (27.7)	30 (39.5)	22 (28.9)	24 (31.6)	
Neither agree nor disagree	7 (2.6)	0 (0)	3 (42.9)	4 (57.1)	
Disagree	22 (8)	6 (27.3)	9 (40.9)	7 (31.8)	
Strongly disagree	6 (2.2)	1 (16.7)	4 (66.7)	1 (16.7)	
Question 2					0.023
Strongly agree	108 (39.4)	42 (38.9)	35 (32.4)	31 (28.7)	
Agree	99 (36.1)	29 (29.3)	38 (38.4)	32 (32.3)	
Neither agree nor disagree	6 (2.2)	0 (0)	2 (33.3)	4 (66.7)	
Disagree	44 (16.1)	11 (25)	10 (22.7)	23 (52.3)	
Strongly disagree	17 (6.2)	8 (47.1)	7 (41.2)	2 (11.8)	
Question 3					0.782
Strongly agree	5 (1.8)	2 (40)	1 (20)	2 (40)	
Agree	30 (10.9)	7 (23.3)	13 (43.3)	10 (33.3)	
Neither agree nor disagree	11 (4)	2 (18.2)	5 (45.5)	4 (36.4)	
Disagree	86 (31.4)	27 (31.4)	27 (31.4)	32 (37.2)	
Strongly disagree	142 (51.8)	52 (36.6)	46 (32.4)	44 (31)	
Question 4					0.493
Strongly agree	35 (12.8)	9 (25.7)	13 (37.1)	13 (37.1)	
Agree	59 (21.5)	18 (30.5)	18 (30.5)	23 (39)	
Neither agree nor disagree	43 (15.7)	19 (44.2)	16 (37.2)	8 (18.6)	
Disagree	82 (29.9)	24 (29.3)	27 (32.9)	31 (37.8)	
Strongly disagree	55 (20.1)	20 (36.4)	18 (32.7)	17 (30.9)	
Question 5					0.672
Strongly agree	89 (32.5)	29 (32.6)	34 (38.2)	26 (29.2)	
Agree	86 (31.4)	29 (33.7)	24 (27.9)	33 (38.4)	
Neither agree nor disagree	38 (13.9)	10 (26.3)	15 (39.5)	13 (34.2)	
Disagree	43 (15.7)	17 (39.5)	11 (25.6)	15 (34.9)	
Strongly disagree	18 (6.6)	5 (27.8)	8 (44.4)	5 (27.8)	
Question 6					0.727
Strongly agree	54 (19.7)	19 (35.2)	22 (40.7)	13 (24.1)	
Agree	77 (28.1)	24 (31.2)	23 (29.9)	30 (39)	
Neither agree nor disagree	43 (15.7)	13 (30.2)	15 (34.9)	15 (34.9)	
Disagree	56 (20.4)	21 (37.5)	15 (26.8)	20 (35.7)	
Strongly disagree	44 (16.1)	13 (29.5)	17 (38.6)	14 (31.8)	

Variable	All N (% col)	Unsupervised N (%row)	Moderated N (%row)	Facilitated N (%row)	P
Question 7					0.754
Strongly agree	40 (14.6)	14 (35)	11 (27.5)	15 (37.5)	
Agree	72 (26.3)	22 (30.6)	26 (36.1)	24 (33.3)	
Neither agree nor disagree	44 (16.1)	17 (38.6)	17 (38.6)	10 (22.7)	
Disagree	62 (22.6)	21 (33.9)	17 (27.4)	24 (38.7)	
Strongly disagree	56 (20.4)	16 (28.6)	21 (37.5)	19 (33.9)	
Question 8					0.797
Strongly agree	50 (18.2)	15 (30)	20 (40)	15 (30)	
Agree	93 (33.9)	29 (31.2)	27 (29)	37 (39.8)	
Neither agree nor disagree	32 (11.7)	11 (34.4)	11 (34.4)	10 (31.2)	
Disagree	49 (17.9)	20 (40.8)	16 (32.7)	13 (26.5)	
Strongly disagree	50 (18.2)	15 (30)	18 (36)	17 (34)	
Question 9					0.874
Strongly agree	14 (5.1)	7 (50)	3 (21.4)	4 (28.6)	
Agree	46 (16.8)	15 (32.6)	16 (34.8)	15 (32.6)	
Neither agree nor disagree	38 (13.9)	10 (26.3)	13 (34.2)	15 (39.5)	
Disagree	92 (33.6)	30 (32.6)	29 (31.5)	33 (35.9)	
Strongly disagree	84 (30.7)	28 (33.3)	31 (36.9)	25 (29.8)	
Question 10					0.118
Strongly agree	33 (12)	13 (39.4)	11 (33.3)	9 (27.3)	
Agree	60 (21.9)	17 (28.3)	15 (25)	28 (46.7)	
Neither agree nor disagree	26 (9.5)	12 (46.2)	9 (34.6)	5 (19.2)	
Disagree	85 (31)	21 (24.7)	35 (41.2)	29 (34.1)	
Strongly disagree	70 (25.5)	27 (38.6)	22 (31.4)	21 (30)	
Question 11					0.354
Strongly agree	51 (18.6)	17 (33.3)	15 (29.4)	19 (37.3)	
Agree	82 (29.9)	29 (35.4)	24 (29.3)	29 (35.4)	
Neither agree nor disagree	64 (23.4)	20 (31.2)	28 (43.7)	16 (25)	
Disagree	60 (21.9)	16 (26.7)	19 (31.7)	25 (41.7)	
Strongly disagree	17 (6.2)	8 (47.1)	6 (35.3)	3 (17.6)	
Question 12					0.641
Strongly agree	35 (12.8)	14 (40)	11 (31.4)	10 (28.6)	
Agree	37 (13.5)	15 (40.5)	10 (27)	12 (32.4)	
Neither agree nor disagree	53 (19.3)	16 (30.2)	20 (37.7)	17 (32.1)	
Disagree	81 (29.6)	20 (24.7)	32 (39.5)	29 (35.8)	
Strongly disagree	68 (24.8)	25 (36.8)	19 (27.9)	24 (35.3)	
Question 13					0.872
Strongly agree	17 (6.2)	7 (41.2)	6 (35.3)	4 (23.5)	
Agree	34 (12.4)	14 (41.2)	9 (26.5)	11 (32.4)	
Neither agree nor disagree	25 (9.1)	8 (32)	7 (28)	10 (40)	
Disagree	79 (28.8)	27 (34.2)	26 (32.9)	26 (32.9)	
Strongly disagree	119 (43.4)	34 (28.6)	44 (37)	41 (34.5)	
Question 14					0.329
Strongly agree	28 (10.2)	10 (35.7)	12 (42.9)	6 (21.4)	
Agree	66 (24.1)	25 (37.9)	15 (22.7)	26 (39.4)	
Neither agree nor disagree	32 (11.7)	13 (40.6)	9 (28.1)	10 (31.2)	
Disagree	71 (25.9)	22 (31)	24 (33.8)	25 (35.2)	
Strongly disagree	77 (28.1)	20 (26)	32 (41.6)	25 (32.5)	

Table 8. **Questionnaire's scores. Observed means and differences from T0, divided into groups and time.**

Time	Unsupervised		Moderated		Facilitated	
	Mean (STD)	Difference from T0 Mean (STD)	Mean (STD)	Difference from T0 Mean (STD)	Mean (STD)	Difference from T0 Mean (STD)
0	36.35 (8.47)	------	37.63 (8.25)	------	36.97 (7.89)	------
1	35.97 (8.32)	-0.37 (2.27)	38.10 (8.51)	0.48 (2.35)	37.29 (8.15)	0.32 (2.44)
2	36.35 (7.55)	0.00 (4.08)	37.85 (8.24)	0.36 (3.76)	37.21 (8.25)	0.17 (3.78)
3	35.61 (7.64)	-0.69 (4.14)	38.41 (8.73)	0.83 (3.86)	36.41 (8.86)	-0.13 (4.42)

Table 9. Questionnaire's scores. Differences in mean transformation among the groups of intervention for time.

	Mean* (SE)	p
Diff. Facilitated-Moderated in TIME1	-0.23 (0.56)	0.68
Diff. Facilitated-Moderated in TIME2	-0.24 (0.56)	0.67
Diff. Facilitated-Moderated in TIME3	-1.03 (0.57)	0.07
Diff. Facilitated-Unsupervised in TIME1	0.76 (0.57)	0.18
Diff. Facilitated-Unsupervised in TIME2	0.25 (0.57)	0.66
Diff. Facilitated-Unsupervised in TIME3	0.63 (0.58)	0.27
Diff. Moderated-Unsupervised in TIME1	0.99 (0.56)	0.08
Diff. Moderated-Unsupervised in TIME2	0.49 (0.56)	0.39
Diff. Moderated-Unsupervised in TIME3	1.67 (0.56)	**0.0033**

*: I estimated the difference between the group of intervention for each time using a linear regression model for repeated measures, considering the correlation between groups of discussion, and correcting for the level of the score at T0, for age, degree and for the number of correct answers to the comprehension questions in T1.

2.2 The 'undecided': results

In addition to this analysis, I decided to make a complementary investigation based on the third answer of the questionnaire's questions: "neither agree, nor disagree". In particular, I measured the shift's percentage from the answer "Neither agree nor disagree" in time T0 to any other answer in the other time points (T1, T2 and T3), as well as the shift's percentage from the answers "Strongly agree"/"Agree"/"Disagree"/"Strongly

disagree" in time T0 to "Neither agree nor disagree" in the time points. I decided to make this additional investigation for two reasons. First, the shift from indecisiveness to an originally defined position might be considered as valuable, in the light of pluralism, since it might mean that deliberation has a role in helping participants taking a position. Second, and more interestingly, the shift from a defined position to an uncertain one might highlight the importance deliberation has in unhinging pre-existing positions, putting them under the scrutiny of reason and mutual exchange, thus leaving participants with potentially constructive doubts.

1) From "Neither agree nor disagree" (T0) to any other answer (T1, T2, T3) **(Table 10)**

As far as those that do not have a specific opinion at T0 ("Neither agree nor disagree") and who afterwards take a position at T1, T2, or T3 are concerned, there are no statistically significant differences between the three groups for any question.

2) From "Strongly agree"/"Agree"/"Disagree"/"Strongly disagree" (T0) to "Neither agree nor disagree" (T1, T2, T3) **(Table 11)**

In T1 and in T2 there are no statistically significant differences between the three groups for any question. In T3, on the contrary, I found significant differences in questions **5-6-9-11**. In particular, the unsupervised group seems to become less decided on a specific ethical position at T3. As I will show in the Discussion, this might be explained in terms of long-term consequences for the supervised groups rather than for the unsupervised ones: the former came to a more definite and considered position in the long run, while those that have been members of an unsupervised group are less prone to have a specific position.

Table 10. Transformation from "neither agree nor disagree" at T0 to other answers at different times, for each group of intervention and for each time.

	T1				T2				T3			
	Unsup. N (% col)	Moder. N (% col)	Facilit. N (% col)	p	Unsup. N (% col)	Moder. N (% col)	Facilit. N (% col)	p	Unsup. N (% col)	Moder. N (% col)	Facilit. N (% col)	p
From "Neither agree nor disagree" at T0 to "Strongly agree"/"Agree"/"Disagree"/"Strongly disagree"												
Question 1	0 (.)	3 (100)	4 (100)	----	0 (.)	3 (100)	4 (100)	----	0 (.)	3 (100)	4 (100)	----
Question 2	0 (.)	2 (100)	4 (100)	----	0 (.)	2 (100)	4 (100)	----	0 (.)	2 (100)	3 (100)	----
Question 3	2 (100)	4 (80)	3 (75)	0.748	2 (100)	2 (40)	4 (100)	0.084	1 (50)	3 (75)	4 (100)	0.335
Question 4	16 (84.2)	13 (81.2)	7 (87.5)	0.924	16 (84.2)	14 (87.5)	8 (100)	0.5	17 (89.5)	11 (68.8)	6 (85.7)	0.28
Question 5	7 (70)	11 (73.3)	9 (69.2)	0.968	10 (100)	13 (86.7)	11 (84.6)	0.443	9 (90)	13 (86.7)	10 (90.9)	0.936
Question 6	8 (61.5)	11 (73.3)	12 (80)	0.55	10 (76.9)	13 (86.7)	14 (93.3)	0.456	12 (92.3)	12 (80)	10 (76.9)	0.541
Question 7	12 (70.6)	11 (64.7)	7 (70)	0.925	15 (88.2)	14 (82.4)	8 (80)	0.826	17 (100)	15 (88.2)	8 (88.9)	0.348
Question 8	8 (72.7)	8 (72.7)	7 (70)	0.987	9 (81.8)	9 (75)	8 (80)	0.917	10 (90.9)	6 (60)	7 (77.8)	0.246
Question 9	10 (100)	10 (76.9)	10 (66.7)	0.131	8 (80)	12 (92.3)	11 (73.3)	0.429	6 (60)	10 (76.9)	11 (78.6)	0.555
Question 10	9 (75)	7 (77.8)	4 (80)	0.973	9 (75)	6 (66.7)	5 (100)	0.357	9 (75)	8 (88.9)	4 (80)	0.726
Question 11	12 (60)	23 (82.1)	6 (37.5)	0.011	16 (80)	25 (89.3)	10 (62.5)	0.105	14 (70)	25 (92.6)	12 (85.7)	0.114
Question 12	12 (75)	15 (75)	10 (58.8)	0.488	13 (81.2)	15 (71.4)	12 (70.6)	0.736	10 (62.5)	14 (73.7)	11 (73.3)	0.73
Question 13	3 (37.5)	5 (71.4)	4 (40)	0.341	5 (62.5)	5 (71.4)	7 (70)	0.92	7 (87.5)	6 (85.7)	7 (70)	0.592
Question 14	5 (38.5)	7 (77.8)	5 (50)	0.187	9 (69.2)	8 (88.9)	6 (60)	0.362	10 (83.3)	7 (77.8)	7 (87.5)	0.867

Table 11. Transformation to "neither agree nor disagree" from different answers at T0, for each group of intervention and for each time.

	T1				T2				T3			
	Unsup. N (% col)	Moder. N (% col)	Facilit. N (% col)	p	Unsup. N (% col)	Moder. N (% col)	Facilit. N (% col)	p	Unsup. N (% col)	Moder. N (% col)	Facilit. N (% col)	p
From "Strongly agree"/"Agree"/"Disagree"/"Strongly disagree" at T0 to "Neither agree nor disagree"												
Question 1	1 (1.1)	1 (1.1)	0 (0)	0.609	1 (1.1)	1 (1.1)	2 (2.2)	0.769	1 (1.1)	1 (1.2)	0 (0)	0.627
Question 2	89 (98.9)	87 (96.7)	88 (100)	0.174	90 (100)	88 (96.7)	88 (98.9)	0.175	87 (97.8)	86 (98.9)	82 (100)	0.392
Question 3	86 (97.7)	83 (95.4)	87 (98.9)	0.35	87 (98.9)	86 (97.7)	87 (97.8)	0.818	85 (97.7)	83 (97.6)	77 (95.1)	0.541
Question 4	68 (95.8)	74 (97.4)	81 (96.4)	0.868	66 (93)	74 (96.1)	82 (96.5)	0.539	66 (94.3)	66 (90.4)	75 (96.2)	0.339
Question 5	77 (96.2)	75 (97.4)	78 (98.7)	0.609	77 (96.2)	76 (97.4)	77 (96.2)	0.893	70 (88.6)	72 (97.3)	71 (95.9)	**0.054**
Question 6	73 (94.8)	75 (97.4)	74 (96.1)	0.707	74 (96.1)	76 (97.4)	75 (96.2)	0.875	65 (85.5)	71 (95.9)	71 (98.6)	**0.003**
Question 7	68 (93.2)	72 (96)	77 (93.9)	0.737	65 (89)	68 (89.5)	79 (95.2)	0.304	68 (94.4)	67 (93.1)	71 (93.4)	0.939
Question 8	75 (94.9)	77 (95.1)	79 (96.3)	0.893	74 (93.7)	80 (98.8)	83 (100)	0.023	74 (94.9)	78 (98.7)	73 (96.1)	0.395
Question 9	78 (97.5)	77 (97.5)	74 (96.1)	0.842	75 (93.8)	72 (90)	75 (96.2)	0.297	68 (86.1)	72 (94.7)	68 (95.8)	**0.051**
Question 10	77 (98.7)	77 (92.8)	83 (95.4)	0.186	73 (93.6)	82 (97.6)	80 (90.9)	0.177	71 (92.2)	74 (92.5)	76 (95)	0.743
Question 11	62 (88.6)	60 (93.8)	70 (92.1)	0.545	64 (91.4)	58 (89.2)	74 (96.1)	0.28	62 (89.9)	51 (82.3)	68 (95.8)	**0.039**
Question 12	71 (95.9)	69 (95.8)	71 (94.7)	0.917	66 (89.2)	66 (91.7)	74 (97.4)	0.139	68 (93.2)	68 (97.1)	69 (98.6)	0.208
Question 13	79 (96.3)	81 (95.3)	80 (97.6)	0.735	75 (91.5)	83 (96.5)	78 (94)	0.386	74 (91.4)	78 (95.1)	71 (94.7)	0.562
Question 14	77 (100)	78 (94)	80 (97.6)	0.072	74 (96.1)	79 (94)	83 (100)	0.091	74 (96.1)	75 (93.8)	73 (94.8)	0.799

2.3 Analysis over participants' perceived legitimacy: results

I carried out a final analysis in order to evaluate what we shall call the participants' *perceived legitimacy*. Apart from the preferences the participants actually and explicitly express in the questionnaires, the participants evaluate some more interactional aspects of the experiment, such as the behaviour of other participants during the discussion, the general tendency of deliberative sessions, the implicit or explicit consensus reached between participants, and so on. With the distinction between a perceived legitimacy and the real legitimacy (the preferences actually expressed) we want to capture the fact that the participants *expressed* preferences do not always correspond to participants *considered* preferences (Gutmann and Thompson 2004), that is the preferences participants would express if they had enough time and information to reflect upon them.

Given this picture, we want to find out to what extent the attitude arising from the answers provided by participants into the questionnaires were then reflected in the evaluative questionnaire, that is, whether, at least in this case, real legitimacy is in line with or distinguishes from perceived legitimacy.

Table 12 shows the data from the evaluation sheet at T2, where the subjects were asked to evaluate the experience they went through. The analysis has been conducted after the deliberative sessions, therefore when participants were still divided into the three experimental arms. Although I have not found any significant difference in the evaluation questions between the three arms, some trends can be seen and, therefore, some preliminary hypotheses can be drawn. First of all, as far as the last question is concerned – that is, "how clear were the questions of the questionnaire?" – half of the participants answered that they were highly clear. Only, 17% of the subjects responded that they were either clear at a small degree (0.9) or moderately clear (16.1). Thus, the first conclusion that can be drawn is that participants found the questionnaire comprehensible.

Another relevant datum regards whether the subjects have felt manipulated by those supervising the experiment. Concerning this last aspect, 89.6% of the subjects declared that they felt as they were not manipulated at all. Obviously the most interesting group in this respect is the facilitated one, where the supervising figure was more active: only 2.6% of those belonging to facilitated groups suffered either a moderate manipulation (1.3%), or a very high manipulation (1.3%). Another very important aspect that might confirm the almost totally absence of any kind of manipulation is the fact that 79.1% of the subjects reported they have been very highly free to express their preferences within deliberative sessions.

The last three data I would like to focus on concern the first three questions of the evaluation sheet, which deal with respect, consensus, and the transformation of preferences. Concerning the first aspect, more than half of the participants (52.6%) reported that the attitude within deliberative sessions was of very high respect towards others' preferences. What can be surprising, however, is that the peak of this perception can be found in the moderated group (60%) rather than in the facilitated (40%) or in the unsupervised one (57.3%). This is very interesting and it will be examined in the session devoted to results' discussion. Something similar can be said as far as consensus reaching is concerned. Despite not being amongst the aims of the deliberative sessions, it appeared rather natural for participants to conceive their task as an attempt to reach a consensus, notwithstanding the explicit instructions provided by the experimenters. Moreover, it is interesting to notice that most of those who responded that consensus-reaching was prompt at a very high degree, were mainly participants belonging to the unsupervised groups. That can be evidence of a trend, which is not, however, significant in the present experiment, to try and reach consensus on these issues.

Finally, concerning the question related to the transformation of preferences, subjects did not perceive that they have changed their minds radically from T0 to T2. Indeed, 43.5% of participants believe they have transformed their preferences only to a small

degree. This statement is quite opposite to the data coming from participants' answers to the standard questionnaires at the different time points.

Table 12 – Participants' perceived legitimacy

Variable	All N (% col)	Unsupervised N (% col)	Moderated N (% col)	Facilitated N (% col)	p
ALL	230 (100)	75 (100)	80 (100)	75 (100)	
Evaluation 1: *How much has the discussion you took part in, promoted an attitude of* ***higher respect towards the preferences of the other participants****?*					0.239
Not at all	2 (0.9)	0 (0)	1 (1.2)	1 (1.3)	
Small degree	6 (2.6)	2 (2.7)	1 (1.2)	3 (4)	
Moderate degree	20 (8.7)	9 (12)	4 (5)	7 (9.3)	
High degree	78 (33.9)	21 (28)	25 (31.2)	32 (42.7)	
Very high degree	121 (52.6)	43 (57.3)	48 (60)	30 (40)	
Evaluation 2: *How has the discussion you took part in,* ***prompt your group to reach a consensus****?*					0.228
Not at all	7 (3)	1 (1.3)	3 (3.8)	3 (4)	
Small degree	14 (6.1)	3 (4)	5 (6.2)	6 (8)	
Moderate degree	50 (21.7)	10 (13.3)	19 (23.8)	21 (28)	
High degree	95 (41.3)	34 (45.3)	34 (42.5)	27 (36)	
Very high degree	61 (26.5)	27 (36)	18 (22.5)	16 (21.3)	
Evaluation 3: *How much has the discussion you took part in, had* ***an impact on the transformation of your preferences concerning the issue at hand****?*					0.542
Not at all	43 (18.7)	12 (16)	20 (25)	11 (14.7)	
Small degree	100 (43.5)	32 (42.7)	37 (46.2)	31 (41.3)	
Moderate degree	60 (26.1)	23 (30.7)	14 (17.5)	23 (30.7)	
High degree	20 (8.7)	7 (9.3)	7 (8.8)	6 (8)	
Very high degree	4 (1.7)	1 (1.3)	1 (1.2)	2 (2.7)	
Evaluation 4: *How much has the discussion you took part in,* ***allowed you to express your preferences in an unconstrained way****?*					0.238
Not at all	1 (0.4)	0 (0)	1 (1.2)	0 (0)	
Small degree	3 (1.3)	2 (2.7)	0 (0)	1 (1.3)	
Moderate degree	6 (2.6)	3 (4)	0 (0)	3 (4)	
High degree	35 (15.2)	10 (13.3)	17 (21.2)	8 (10.7)	
Very high degree	182 (79.1)	60 (80)	61 (76.2)	61 (81.3)	
Evaluation 5: *Do you think you have been somehow manipulated towards a specific position* ***from the person who supervised the discussion****?*					0.105
Not at all	206 (89.6)	70 (93.3)	75 (93.8)	61 (81.3)	
Small degree	16 (7)	3 (4)	3 (3.8)	10 (13.3)	
Moderate degree	2 (0.9)	1 (1.3)	0 (0)	1 (1.3)	
Very high degree	1 (0.4)	0 (0)	0 (0)	1 (1.3)	
Evaluation 6: *How* ***clear*** *were the questions of the questionnaire?*					0.109

Small degree	2 (0.9)	1 (1.3)	1 (1.2)	0 (0)	
Moderate degree	37 (16.1)	19 (25.3)	11 (13.8)	7 (9.3)	
High degree	115 (50)	38 (50.7)	40 (50)	37 (49.3)	
Very high degree	72 (31.3)	17 (22.7)	26 (32.5)	29 (38.7)	

3. Discussion

The theoretical thesis presented in the first part of this dissertation was grounded in the purely theoretical intuition according to which the bioethicist might have a role within the public sphere, in particular within public decision-making, acting as a facilitator of deliberation in cases of bioethics sensitive issues. The results of the pioneering lab experiment carried out in order to test such an idea seem to suggest, nevertheless, rather different considerations. Before analysing them in details, let me briefly recall the parameters I chose to measure the relevance of the facilitator, in order to make it clear how much distance there is from the results we gained and the theoretical starting point.

Several research questions have been investigated through this experiment. Some of them are more focused on participants' perceived legitimacy, some others on material's comprehension and indirect aspects of the deliberative process. However, the most relevant question concerned the impact of the facilitator towards the endorsement, by the participants, of a perspective broadly conceived as pluralistic. The reason for this choice is twofold. First of all, as a matter of fact the vast majority of scholars dealing with deliberation, practically considered, are engaged with investigating to what extent and how much deliberative sessions appear to have a role in inducing participants' transformation of preferences. However, as some sceptics have pointed out, "in itself opinion change tells nothing about whether judgments represent 'enlightened preferences'" (Smith 2009, 95). In other words, opinion change cannot be considered as the proof of the success or failure of the facilitator, since the mere transformation of preferences does not vehicle any value's perspective. This fact appears deeply in contrast with the explicitly value-laden perspective endorsed here: a pluralistic viewpoint which grants a privileged role to deliberation as the most legitimate means for helping citizens to develop considered preferences over the

mostly relevant bioethical topics currently discussed within the public arena, with the very ultimate purpose of prompting a more aware and respectful citizenry. Moreover, looking at the data on the basis of the question concerning participants' perception of their transformation of preferences, only about the 10% of the participants declared that the discussion changed with very high degree or just with high degree their preferences, whereas about 60% of the participants have replied between "not at all" and "small degree" to the same question (see **Table 12**). However, results from a preliminary analysis show that participants, independently from the specific arm they belonged to, massively changed their preferences. In particular, only 3 participants out of 274 have not change their preferences from T0 to T2 (1.1%), and 172 participants (62,77%) have changed their preferences for at least 6 questions out of 14 from T0 to T2 (see **Table 13**).

Table 13 – Questions and opinion change

Number of questions in which participants changed their answer	Number of participants who change the answer (% col)
0	3 (1.1)
1	6 (2.2)
2	12 (4.3)
3	18 (6.5)
4	28 (10.1)
5	37 (13.4)
6	34 (12.3)
7	42 (15.2)
8	33 (12)
9	25 (9.1)
10	14 (5.1)
11	16 (5.8)
12	8 (2.9)

In other words, a second reason for rejecting opinion change as a valuable means for evaluating the goodness of the facilitator lies also in the discrepancy between participants' actual transformation of preferences and what they have perceived and hence declared. This, in turn, raises some doubts as to how evaluating such a change in preferences –

whether ascribing it to a genuine reconsideration, by participants, of their preliminary viewpoints, or to the (intentional or non intentional) manipulative behaviour of the facilitator, or to other still unclear reasons – making eventually difficult to ascribe to opinion change a real positive value.

Once the reasons for the adoption of opinion change towards pluralism broadly conceived are clear, let me briefly report what are the main results we observed, so as to properly discuss them. As already pointed out, I did not observe statistically significant differences between the moderated and the facilitated group as well as between the facilitated and the unsupervised one. However, if observed singularly as opposed to the unsupervised group, data contained in **Table 8** and **Table 9** showed that the moderated group presents a statistically significant difference with respect to the unsupervised group at T3, as compared to T0. In particular, at T3 the moderated group shows a median difference opposed to T0 of 0.48 (STD:2.35), whereas the unsupervised group it is of -0.37 (STD:2.27) (**Table 8**), with a p-value of the 0.0033 (**Table 9**).

This result can be better discussed by splitting it into the two discoveries I obtained: first, the fact that opinion change occurred not just after the deliberative session, but some time after the experiment was carried out; second, the fact that the moderated group is the one that appears to have significantly transformed its preferences in the direction of a more pluralistic perspective.

Concerning the first result, it can be argued that the fact that deliberation proves to have much more long-term rather than short-term effects is not at all surprising. Indeed, several scholars have raised some doubts as to whether deliberation can actually be considered as a useful learning process, above all when devised as 'one-shot' event. To give an example, some interviews conducted by Chlivers reported that those who attended deliberative experiments repeatedly asked to have "enough time […] to become informed and develop a competent understanding" (Chlivers 2008, 174). The same evidence is confirmed by the very final part of our evaluative questionnaire, in which participants were asked to express

their opinions as to what could have significantly improved the experiment. Several students reported precisely the need to extend the time devoted to deliberation and, some others, explicitly proposed to introduce this activity as part of the academic path. Despite being aware that deliberation has higher potential if conceived as "an extended learning process" (Chlivers 2008, 174) repeated during the course of time, I had to constrain the deliberative sessions to 75 minutes due to time and costs constraints.

The second result is, in any case, the most interesting one with respect to the primary research question: the impact of the facilitator over participants' preferences. However, the moderator and not the facilitator appeared to be the one who prompted the participants towards the adoption of a pluralistic viewpoint. A possible interpretation is that participants are more willing to consider viewpoints different from their initial ones, thus accepting to revise the latter, when these different perspectives come from their peers rather than from a person fulfilling a superior role. In other words, the non-directive but still corrective role the facilitator was asked to perform in order to vehicle valid (both scientifically and logically) information, most probably induced in the participants a defensive attitude which, in turn, produced the rejection rather than the acceptance of a deeper consideration of their initial preferences. Moreover, there is evidence that individuals are more prone to accept positions and arguments that are in line with their pre-existing beliefs (Himmelroos 2013). Indeed, "although many theorists see the exposure to dissimilar views as beneficial for deliberation (e.g., Calhoun 2002; Manin 2005; Mutz 2002), scholars repeatedly uttered concerns about its practicability. Evidence from naturally occurring deliberation suggests that people prefer to discuss with like-minded (Mutz 2006). Huckfeldt *et al.* (2004, 7) note that this human trait may either be attributed to its Downsian desire to reduce (information) costs or to the psychic discomfort that encountering disagreement may produce. While the former condition could possibly be altered by putting people holding dissimilar views together in one room (as in DP), the latter would pose greater hindrances to successful deliberation. Thus, in case of

disagreement, people might not necessarily be inclined to confront the dissent with a counter claim, but rather opt for an escape strategy" (Gerber 2011, 4-5). This insight can explain why the moderated group shows a more significant effect as compared to the facilitated one. The role of the moderator is simply to respect and prompt equal contribution by each participant – by "encouraging silent participants to speak or slowing down too dominant participants" (Young 2000) –, while the role of the facilitator is a more disruptive one since he has to prompt reflection on expressed preferences by displaying either different viewpoint or likely consequences of one's preferences. The former does not question participants' preferences, while the latter does. It can, thus, be hypothesised that, for participants of moderated group, it was easier to conform to a more pluralistic viewpoint because they do not acquire a defensive attitude – or they do not opt for an escape strategy – during the deliberative session. Given time constraints and the fact that those who took part in the facilitated group might have experienced this defensive attitude, it can be hypothesised that the result showing a difference between moderated and facilitated groups can massively depend on that.

Such a result might lead to four different practical scenarios. The first one, which is also the simplest one, is to literally consider this result and to evaluate this experiment as a valid proof for the maintenance of moderators within deliberative based experiments, perhaps suggesting to standardize this figure in line with the third role ascribed by us to the facilitator (which was conceived as that part of the facilitator that overlaps with the moderator). A second option would be to maintain the presence of someone behaving similarly to our facilitator, so as to partially preserve the corrective role of the latter, but to choose him/her amongst the participants. In other words, during the process of enrolment, while the vast majority might be enrolled as simple participant, some citizens might be trained as facilitators. However, two problems might still arise with this second option. First, it cannot be excluded that the same reaction participants showed in our experiment towards the professional facilitator can be observed also with respect to the 'bottom up'

facilitator. Second, precisely because he is not a professional facilitator both the neutrality requirement and the absolute validity of the scientific and ethics information might be put in serious danger. Finally, precisely in order to preserve the validity of the information, the bioethicists should be rethought so as not to part of the deliberative process but to have a fundamental role in the preparatory phase of the experiment, preparing the material and validating it.

A final consideration might be added concerning the additional analysis carried out on those who mostly replied: “neither agree nor disagree”. As already said, in T3, in questions **5-6-9-11** significant differences have been found regarding as far as the shift from “Strongly agree”/“Agree”/“Disagree”/“Strongly disagree” (T0) to “Neither agree nor disagree” (T1, T2, T3) concerns. In particular, the unsupervised group seemed to become less decided on a specific ethical position at T3.

These data can be interpreted as follows: since the discussion in the unsupervised group was not guided in any way, participants come to some temporary conclusions through facing other members’ perspectives in their group, and these conclusions determine how they respond to the questionnaire at T2. However, precisely because these conclusions are not reached by a guided discussion, they do not have long-term consequences on the participants’ preferences. For this reason, they are not maintained in T3.

In addition to the aforementioned considerations, the results obtained clearly highlight the weak points of this type of experiments and how further similar ones should be designed. First of all, both the time devoted to the single deliberative round and the occurrence of the entire deliberative event should be broadened, so as to make the former more able to let participant have enough time to revise their preferences, and the latter to be really a learning effective process. A second improvement might be to perform the randomization not during the experiment but before it so as to be sure that the small discussing groups are homogeneous concerning gender and education. Finally, the informative material should be combined with a different kind of informational source, for

example a short movie, so as to enable also those who are less familiar with printed material to have a chance of engaging in an informed discussion.

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CONCLUSIONS

The present work has aimed to provide a contribution to the current debate on the issue of bioethical expertise – that is, whether an expertise in the field of bioethics exists, what kind of knowledge ethical/bioethical knowledge is, and, above all, who should be entitled to take decisions on bioethical issues of public interest. However, far from simply addressing such a debate from a general standpoint, it soon became clear that the specific subject of my investigation was the professional figure of the bioethical expert as located within the public arena. Since this particular path appeared largely underexplored within the current literature, I could not benefit from a pre-existent methodology, and I was thus compelled to find an alternative strategy to pursue. This was to link the traditional debate on bioethical expertise to the specific domain where such an issue should be investigated. In particular, far from inferring the public mandate of the expert from theoretical speculations, my analytic strategy was to reverse the approach and to infer the role of the bioethical expert by looking at those values the expert was expected to preserve and promote within the public sphere.

In recognition of these considerations, the core normative proposal on which this thesis is grounded started to take shape. According to this model, the bioethicist might exercise a prominent role also within the public sphere while being respectful of its liberal tenets, as long as the former behaves as a *facilitator of deliberation in cases of bioethically sensitive issues*, which meant, in this view, fulfilling three main functions: first of all, *enhancing non experts' autonomy*, by prompting them to consider some values such as comprehension, self-reflection, critical thinking and critical reasoning. Secondly, *promoting public-spirited perspectives* by showing the importance of pluralism awareness and mutual respect, especially in the public sphere. Thirdly, by *acting as a mediator*, the facilitator has to promote some cooperative and relational values, amongst which equal participation and non-domination over other viewpoints.

The consideration of bioethical expert this model appeared to have was, therefore, that

of someone who, in addition to a procedural expertise, also appeared to be endowed with a *substantial* expertise, meaning that he/she, in order to be so defined, had to possess some knowledge regarding the bioethical matters under discussion. More specifically, I held that a good facilitator is someone who possesses a competence not only in the procedural skills of the deliberative processes – good interactional skills, ability to manage the most commonly occurring group dynamics etc., but also a substantive knowledge of the issue (broadly considered) under debate. This latter aspect should not be interpreted as if the expert were endowed, in this view, with a superior decisional authority with respect to non-experts. By contrast, it just argued there are some substantial reasons, mainly based on the content of bioethics, that support the idea that philosophers are best equipped as bioethical experts, which, however, legitimises us just to consider them as *conceptualizers* of moral issues, rather than as problem-solvers.

In what follows I would like to recall very briefly two very relevant features of this dissertation: the philosophical justification lying behind the figure of the facilitator and some possible implementations of this ideal in the light of the lab experiment carried out and discussed in the fourth chapter of the thesis.

The philosophical justification for the introduction of the facilitator within public decision-making was related here to the influence this figure might have with respect to the development of the so-defined *considered judgments of non-experts*. The answer to the question, asking why was it so important that participants developed judgments that appeared considered lies, in my view, in the qualitative distinction between the private and the public with respect to individual responsibility. The answer provided here was indeed that deliberators, whoever they are, are implicitly obliged to adopt a self-critical attitude within the context of public decision-making (in this case, public bioethics), since the decisions to be taken would be mutually binding for the entire population. Hence, far from considering the development of considered judgments as a supererogatory activity left in the hands of the single individuals, the binding nature of decisions at a public level would

make such a move (from pre-existent to considered judgments) a strict obligation. In other words, and making use of an analogy, one might rephrase what has just been said by claiming that the resolution of moral disagreements recalls the presence of considered judgments, while the resolution of moral dilemmas, primarily affecting the subject taking the decision, does not make this action as necessary.

The above-mentioned idea was defended, within the thesis, through the endorsement of what was defined here as 'the consideration principle', intended as a variation of the Brennan "competence principle". If the latter argued in favour of both possession of the required knowledge and reasonableness of decision-makers and decision-making processes as necessary conditions to have an active role within the public sphere, the principle presented here just endorses 'moral reasonableness' as the necessary unavoidable requirement in order to enter the public sphere. The consideration principle indeed claims that when a decision has high stakes and its outcomes are mutually-binding, it must be made through a process of mutual exchange of considered opinions by reasonable people. In other words, in contrast to Brennan's principle, I rejected the idea that 'knowledge-possession' has to be considered as a precondition for granting the electorate with political power (in this case some kind of power over bioethical issues) within the public sphere. However, if developed, such a principle and the view it conveys would remain just theoretical as in Brennan's view. This is precisely the reason why the facilitator was introduced, thus considering such a figure as guarantor of the consideration principle and, therefore, of the participants' development of considered opinions concerning bioethical issues.

Despite the interesting ideas conveyed by the theoretical thesis just presented, the results of the experiment carried out in order to test such an idea seem to suggest rather different considerations. Indeed, I observed that the moderator and not he facilitator appeared to be the one who prompted the participants towards the adoption of a pluralistic viewpoint, which constituted my primary aim. Several explanations were provided but,

above all, the fact that participants did not appear willing to recognize the goodness of viewpoints which were different from their initial ones, thus agreeing to revise them, only as long as their peers, and not people fulfilling a superior role, made them reflect upon them. In other words, the non-directive but still corrective role the facilitator was asked to perform in order to convey valid (both scientifically and logically) information, most probably induced the participants to develop a defensive attitude which, in turn, produced the rejection rather than the acceptance of a deeper consideration of their initial preferences.

Obviously, these considerations led to a partial rethink of the way in which I believed that the figure of the facilitator might be implemented. The proposal was to make use of this figure only in public debates involving ethical issues and only for *advisory purposes*. In particular, I proposed to involve a facilitator every time we needed the viewpoint of the general population in the case of legal proposals, formulations, implementations or revisions, or simply in situations that could have been defined, directly or indirectly, as infused with ethical issues. In other words, the proposal conveyed here was to rethink the way in which public bioethics is now working, building a mixed institutional setting, which is both expertocratic and non-expertocratic. The non-expertocratic part of the system would be made up of public deliberation processes empowered with the figure of the facilitator. In particular, public deliberations, according to this view, should take the institutional form of mini-publics and, in particular, should be conceived as *mixed versions* of the first (educative forum) and the second (participatory advisory panel) subtypes of mini-publics. Indeed, even if the aim of this first part of the mechanism is purely advisory, what is obtained through public deliberation should at least have some indirect linkage with the social ethical choices decision-makers are going to make. Once the will of the people was clearly established, the final outcome would be passed on to an expertocratic body, this being the same legislative body, or a subgroup of it, working on the bioethical topic, which will work to find the most appropriate and feasible way of actually realizing it

legally.

Even if the general scenario does not seem to require robust changes, thanks to the results obtained, some changes still need to be made and, in particular, the role here attributed to the figure of the facilitator should be transferred to the one of the moderator. In other words, one possible proposal would be to literally consider this result and to evaluate this experiment as a valid proof for the maintenance of moderators within deliberative based experiments, perhaps suggesting standardizing this figure in line with the third role ascribed by us to the facilitator (which was conceived as that part of the facilitator that overlaps with the moderator). A second option would be to maintain the presence of someone behaving in a similar way to that of the facilitator, so as to partially preserve the corrective role of the latter, but to choose him/her from amongst the participants. Finally, precisely in order to preserve the validity of the information, the bioethicists should be rethought so as not to be part of the deliberative process but to have a fundamental role in the preparatory phase of the experiment.

However, as already said, the trend that has been found (0.07) regarding the effect of the facilitator with respect to the moderator at the time point T3, suggested also that the hypothesis of the facilitator might be still valid, provided that another experiment with an increased number of participants as well as an increased amount of time devoted to deliberation is performed.

To conclude, even if still a lot of work needs to be done with regards to the theoretical proposal conveyed here, the importance of the *participatory turn* in addition to the not so tacitly accepted imperative of improving the quality of public decision-making seems nevertheless to suggest that the figure of the bioethical expert in its guise of facilitator of deliberation deserves further attention, and is thus worthy of being explored in greater depth.

Appendix 1

GENETIC TESTS AND REPRODUCTIVE CHOICES
INFORMATIVE MATERIAL

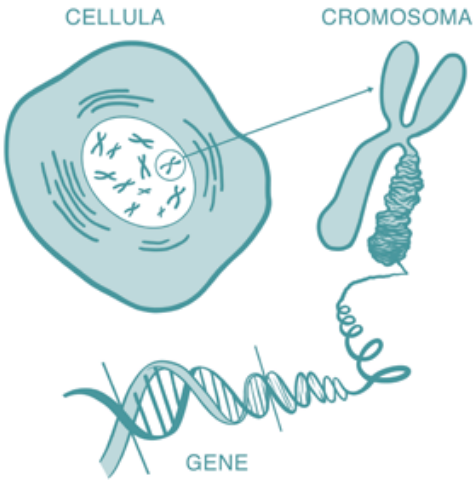
WORDS HIGHLIGHTED IN RED ARE DEFINED IN THE GLOSSARY AT THE END OF THE INFORMATIVE MATERIAL

Introduction: genes and chromosomes

The human body is made up of approximately 100,000 billion cells. Almost all cells contain a set of chromosomes, which carry genetic information. A gene is a heritable region on the DNA, from which an RNA molecule, associated with a particular function, is synthesized. The human genome is made up of thousands of genes (20,000 - 25,000 depending on the particular calculation). Genes control all cellular functions and have a fundamental role in the determination of many characteristics, such as eye colour, blood group and height.

Genes are contained on long, linearly condensed filaments, called chromosomes. *Homo Sapiens* have 46 chromosomes (22 pairs of autosomal or not sex chromosomes, and one pair of sex chromosomes, X and Y). A person's chromosomes are inherited from his/her parents, 23 from the mother and 23 from the father. Thus, there are usually two copies or versions of each gene, termed alleles.

Chromosomes and genes are made up of a chemical substance called deoxyribonucleic acid or DNA.



A genetic disorder is a disease caused by an alteration in the genetic material present in the cells, involving one or more genes. A genetic disorder can be *inherited*, if passed from parent to child (in this case, the mutation is present in the DNA in the oocyte or sperm), or can emerge after conception or during pregnancy, in which case the disease is referred to as a congenital, rather than inherited, genetic disorder.

A separate discussion applies to cancer, where, in general, cells accumulate genetic mutations during a person's life that lead to their uncontrolled proliferation.

Genetic disorders are usually classified as:

a. *Chromosomal disorders*. Chromosomal disorders derive from variations in the set of human chromosomes. Since each chromosome contains thousands of genes, chromosomal alterations usually result in very serious clinical syndromes, i.e., a set of medical signs and symptoms that are associated with one or more disease (somatic abnormalities, growth retardation, mental delay, etc.).

There are two types of chromosomal variations that can determine the onset of a disorder: numerical (alterations in the number of whole chromosomes, referred to as aneuploidy or polyploidy) and structural (alterations in the integrity, copy number and sequence direction within the chromosomes, due to translocations, insertions, deletions, duplications, etc.).

➔ *An example of a chromosomal disorder is Down's syndrome. This disorder is a numerical chromosomal disorder, specifically an aneuploidy disorder. It is also known as trisomy 21 because all the body's cells contain 3 copies of chromosome 21. The life expectancy of individuals with Down's syndrome is about 60 years. This syndrome is the most common chromosomal abnormality in humans: it appears in 1 out of 700/1000 live births. The only other viable trisomies are Edward's syndrome (abnormality in chromosome 18) Patau's syndrome (abnormality in chromosome 13) and Kleinfelter's syndrome. All other trisomies are non-viable. The only viable monosomy is Turner's syndrome.*

b. *Monogenic or single-gene disorders*. Monogenic or single-gene disorders are caused by mutations in a single gene (point mutations or genetic mutations). Monogenic disorders are classified as autosomal (if the mutation occurs in a gene on a non-sex chromosome) or X/Y-linked (if the mutation occurs in a gene on a sex chromosome). Autosomal disorders can also be classified as dominant or recessive. An autosomal disorder is dominant if the mutation of a single allele is sufficient for the disease to manifest itself, and recessive if both alleles need to be mutated.

➔*An example of a monogenic disorder is Hungtington's disease, which is a dominant autosomal disorder. This disease is caused by the mutation of one of the two alleles of the Huntington gene. Disease onset usually occurs in individuals between 30 to 50 years of age, after which the disease progresses slowly, but is fatal after 16-20 years. The incidence of this syndrome is 5-10 cases per 100,000 people.*

c. *Multifactorial inheritance disorders*. Multifactorial inheritance disorders are caused by a combination of multiple factors, including genetic and environmental factors and their reciprocal interactions.

➔*An example of a multifactorial inheritance disorder is diabetes mellitus. Diabetes is a chronic disease that is characterized by the presence of elevated levels of glucose in the blood due to alterations in the amount or function of insulin. Insulin is a hormone produced by the pancreas that allows the absorption of blood glucose into intestinal mucosal cells, where it is used as an energy source. When this mechanism is impaired, glucose builds up in the bloodstream. There are different types of diabetes (type 1, type 2 and gestational diabetes), all of which are considered as*

multifactorial disorders. The incidence of this disease is about 1 in every 20 people[1].

Genetic analysis

A genetic test or analysis aims to detect (or exclude the presence of) DNA modifications associated with genetic disorders through the analysis of specific genes or chromosomes.

Genetic analyses are usually performed on blood or tissue samples.

What are genetic tests used for?

A genetic test is a tool used to determine:

i) If a person has a genetic disorder (*diagnostic purpose*).

ii) A person's predisposition to develop a specific genetic disorder (predictive purpose, in particular in cases where there is a family history of the disease).

iii) Individual genetic variations, knowledge of which permits the selection of the most appropriate treatment for a specific person (*pharmacogenomics purpose*).

What can genetic tests tell us?

To understand what a genetic test can tell us about a given genetic disorder it is important to understand the concepts of penetrance and genetic risk.

Penetrance

Penetrance is the frequency (expressed as a percentage) with which a characteristic linked to a particular gene, and thus to a corresponding genetic disease, is displayed in individuals carrying a given mutation. The concept of penetrance is of primary importance in the debate on genetic testing because it indicates the frequency with which a particular genotype determines, *at the population level,* the appearance of a corresponding genetic disorder.

There are two types of disease penetrance: complete and incomplete. Penetrance is *complete* when 100% of carriers of a certain genotype display the typical phenotype associated with that genotype (e.g., Down's syndrome is a genetic disorder with complete penetrance because everyone who has a trisomy of chromosome 21 is affected by the syndrome). Penetrance is *incomplete* when less than 100% of carriers display the typical phenotype (e.g., Huntington's disease is a genetic disorder with incomplete penetrance because not all individuals carrying a mutation in the disease-causing gene develop the disease).

For diseases with complete penetrance, the individual will know that, at the population level, the presence of the genotype determines the presence of the disease in all cases. For diseases with incomplete penetrance, the individual is less facilitated in the choice he/she has to make because he/she does not know whether the observed genotype will give rise to the corresponding genetic disorder.

Genetic risk

"Genetic risk" is the probability that an individual carrying one or more mutations associated with a genetic disorder will actually suffer from the disease. Penetrance is linked to single mutations, while genetic risk takes into account all of the mutations present

in an individual. Thus, there may be individuals carrying several low penetrance mutations, which when considered together, increase the genetic risk of that individual.

Genetic tests and reproductive choices

By "reproductive choices" we mean the decisions that one has to make as a prospective parent regarding whether to procreate, with whom, under what conditions, when, etc.

To help a person to make these decisions, genetic testing can be carried out on the prospective parents and on the embryo, either before implantation in the uterus or during pregnancy.

Genetic tests on prospective parents are performed using small blood samples and/or saliva and are used to determine whether the parent is a healthy carrier, suffers from a certain disease, or neither of these alternatives.

For the embryo/foetus, two types of genetic tests can be performed: prenatal diagnosis and preimplantation genetic diagnosis.

Prenatal Diagnosis (PD)

PD refers to all techniques that reveal the presence of disease (genetic and non-genetic) in the foetus. These techniques are performed during pregnancy and may be invasive or non-invasive.

Invasive techniques (amniocentesis and chorionic villus sampling) are reimbursed by the National Health Service for pregnant women over 35 years old at the time of delivery. In contrast, non-invasive techniques, such as maternal blood tests, are paid for by the pregnant woman.

Non-invasive techniques include:

- *Ultrasound.* Ultrasound is a radiological investigation that does not use ionizing radiation but ultrasounds (it is therefore risk-free), and which is used routinely during pregnancy to assess gestational age, to monitor foetal growth, to identify twin pregnancies, and to determine the sex of the unborn child. Ultrasound tests are able to diagnose anatomical malformations that are often transmitted as a multifactorial disorder, but cannot identify specific biochemical or molecular defects (it detects chromosomal alterations but not genetic or point mutations).

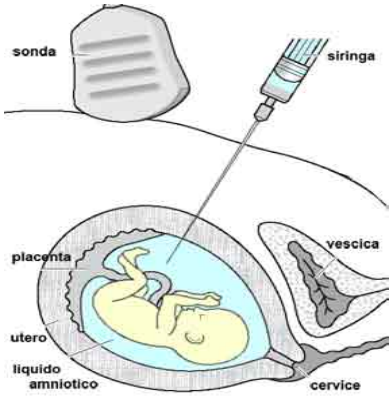
- *Screening of maternal blood (in particular, triple and quadruple tests on maternal blood).* Triple and quadruple screening tests are carried out between the 15^{th} and 18^{th} gestational week and are performed using a simple blood test. These tests assess the concentrations of specific substances present in the maternal blood that are produced by the foetus and the placenta. The triple test measures the amounts of three substances: alpha-fetoprotein (AFP), beta-human chorionic gonadotropin (bHCG) and unconjugated estriol (E3 FREE). The quadruple test measures the amounts of inhibin A in addition to the substances in the triple test. These analyses evaluate the foetus' genetic risk for developing a particular disease, but cannot diagnose with certainty the actual presence of the genetic disease.

- *Non-invasive tests to detect foetal DNA in maternal blood.* These tests are early diagnostic tests that are performed from the 9^{th} week of gestation. They are precise and reliable tests, as well as safe as they require a normal sample of maternal blood. This technique assesses the risk of having some foetal

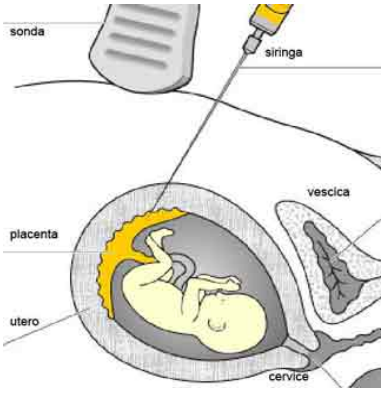
chromosomal abnormalities (such as Down's syndrome or other syndromes that are derived from alterations of the sex chromosomes). The reliability of these tests in detecting these abnormalities is 99%.

Invasive techniques[2]:

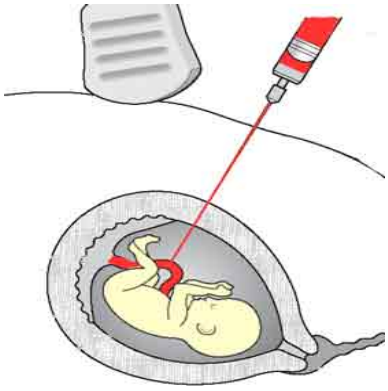
– *Amniocentesis.* Amniocentesis is performed through trans-abdominal sampling of the amniotic liquid* after the 15th week of gestation* (16) under ultrasound guidance. The risk of miscarriage is low but not negligible (less than 1%).



- *Chorionic villus sampling.* Chorionic villus sampling involves trans-abdominal sampling of placental villi under ultrasound guidance after the 10th gestational week. The risk of miscarriage is the same as or slightly higher than that in amniocentesis[3].



- *Cordocentesis.* Cordocentesis involves sampling of foetal blood after the 18th gestational week (20). The risk of miscarriage is 2-3%.



How to choose between the different invasive and non-invasive techniques?

Both amniocentesis and chorionic villus sampling allow the detection of chromosomal abnormalities (karyotype*) and microscopic rearrangements*. Genetic testing is not carried out unless there is some indication that a specific genetic disease might be present, such as a family history. This is because it is not possible to test for all genetic disorders since they are numerous and not all are known. It is therefore possible for a child to be born with a genetic disorder despite having a karyotype result that appears negative for chromosomal mutations. The main differences between amniocentesis and chorionic villus sampling are the time at which the tests are performed (chorionic villus sampling is usually performed between the 11^{th}-12^{th} gestational week and amniocentesis between the 16^{th}-18^{th} gestational week) and the length of time required to obtain results (a few days for chorionic villus sampling and 2-3 weeks for amniocentesis).

The choice of technique depends on the following factors: gestational week, the likelihood that a chromosomal abnormality is present, and the desired level of confidence in the results, which is influenced by the efficacy and sensitivity of the test.

The reliability of PD varies depending on the technique. The reliability of non-invasive techniques, such as ultrasound, is between 59-80%, while that of invasive techniques, such as amniocentesis and chorionic villus sampling, is close to, although not quite, 100% (99%).

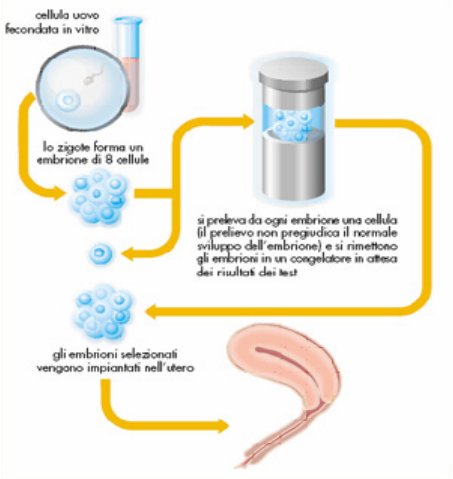
The reliability of the non-invasive technique, maternal blood screening, is 99% but, unlike amniocentesis and chorionic villus sampling, this technique is limited to just a few specific chromosomal abnormalities.

Preimplantation genetic diagnosis (PGD)

PGD is a complementary procedure to PD that detects genetic disorders in embryos generated through medically assisted reproduction*. PGD is used by couples with a high reproductive risk for a given genetic disorder and is carried out at very early stages of embryonic development, before implantation* of the embryo in the uterus.

Thus, in contrast to PD tests, PGD tests are not performed during pregnancy but earlier (before the embryo is implanted in the uterus).

This allows a choice to be made as to whether or not to implant an embryo presenting a genetic disorder.



PGD is performed through the following steps:

a. Induction of ovulation. Ovulation is artificially induced by ovarian stimulation*. The purpose of this stimulation is to induce the maturation of multiple follicles* in the patient in order to obtain more oocytes and thus more embryos to transfer.

b. Oocyte retrieval. This is performed via transvaginal ultrasound. The aspirated fluid is sent to the laboratory for collection of mature oocytes.

c. Medically assisted reproduction. This is the artificial fertilization of the oocyte by male sperm. The technique typically used for artificial fertilization is ICSI (*Intracytoplasmic Sperm Injection*). This technique ensures a greater precision of the fertilization process by injecting sperm directly into the cytoplasm of a single oocyte.

d. Harvesting of embryonic cells. On the third day after fertilization, the embryo usually consists of 6-8 cells. One/two of these cells are collected by introducing a glass micropipette in an opening in the 'zona pellucida' (the wall that surrounds the embryo until the blastocyst* stage) and gently aspirating. This procedure does not interfere with the subsequent development of the embryo.

e. Analysis of harvested cells to test for the presence of genetic mutations associated with the genetic disorder under investigation.

f. Implantation in the uterus of embryos displaying no genetic defects, unless otherwise indicated by the parents.

PGD is able to detect the genetic disorder under investigation in 95% of cases, but fails to detect in 5% of cases[4]. This means that, in the case of a disease with a rate of onset of 1%, the probability that the child who was positive in the PGD test will be born with the disease is 1 in 20 x 1 in 100, i.e., 1 in 2000[5].

GLOSSARY

Allele. One of a pair of genes that appear at a particular location on a particular chromosome and control the same characteristic.

Amniotic liquid. A liquid composed mainly of water, mineral salts, lipids and proteins produced by the placenta and by the membranes that surround the uterine wall in early pregnancy.

Blastocyst. The embryo during the early stages of its development. This phase corresponds to the 5-7th day of fertilization.

Chromosome. Elongated filaments present in the nucleus of animal and plant cells, and comprised of a single DNA molecule that holds the genetic information. Members of each species typically have the same number of chromosomes in their cells.

Chronic disease. A stationary or slowly progressive disease.

DNA. Deoxyribonucleic acid, which carries hereditary information and is found almost exclusively in the nucleus of the cell.

Follicle. Spheroidal cellular aggregation present in the ovary that contains the oocyte.

Genome. The set of DNA sequences in the nucleus, including all genes and other sequences.

Genotype. The genetic and hereditary characters of an individual or population that result in a phenotype.

Gestation. The period between conception and birth during which the development of the foetus takes place.

Implantation. Implantation of the fertilized oocyte in the wall of the uterus.

Karyotype. The profile of chromosomes in a cell defined by their number, size, shape and dimension. The karyotype is specific for each species, organism and cell type.

Medically assisted reproduction. All procedures involving the processing of human oocytes, sperm or embryos with the aim of resulting in a pregnancy.

Miscarriage. Miscarriage is the premature termination of a pregnancy. This may be due to natural causes (spontaneous) or induced.

Mutation. A random variation in the genetic makeup of an individual animal or plant that causes a change in protein synthesis and in the transmission of characteristics.

Oocyte. The female gamete.

Ovarian stimulation. Application of a stimulus to the ovaries to stimulate the production of oocytes.

Phenotype. The set of morphological characteristics of an individual, resulting from the interaction between their genetic material and environmental factors.

RNA. Ribonucleic acid is a molecule similar to DNA that is contained in the nucleus and cytoplasm of cells and is required for protein synthesis.

Translocation. The physical movement of genome sequences inside the nucleus that change their position on chromosomes.

FOOTNOTES

1 This estimation is based on study according to which there would be 347 million people with diabetes mellitus worldwide today (for further information: http://www.who.int/mediacentre/factsheets/fs312/en/).

[2] Invasive diagnosis can be performed in the following cases: a) in women older than 35 years at time of delivery; b) in parents carrying chromosomal translocations or aneuploidy of sex chromosomes; c) in women who previously gave birth to a child with chromosomal abnormalities; d) following detection of foetal malformations by ultrasound scan; e) following a positive nuchal translucency scan (ultrasound scan assessing the quantity of the fluid in the nape of the foetal neck) or triple test (biochemical analyses performed on a blood sample, which quantifies the risk of chromosomal abnormalities in the foetus); f) for the detection of infective agents in the amniotic fluid; g) for studies on foetal DNA; h) for the determination of metabolites in the amniotic fluid.

[3] There are some reports indicating a higher risk of miscarriage for chorionic villus sampling with respect to amniocentesis. In reality, the higher rate of miscarriage reflects the higher risk of a spontaneous miscarriage in the first trimester, when chorionic villus sampling is performed. Thus, the two methods carry equivalent risks of miscarriage.

[4] This is due to various factors: i) possible contamination of the sample with foreign material. ii) Inability to amplify one of the two alleles for technical reasons, and consequently the mutation is not detected (phenomenon known as Allele Drop Out). iii) Mosaicism: when cells derived from the same embryo present different karyotypes. Thus, some cells within an embryo could be normal, while others are mutated. Depending on the precise cells that are sampled, the cytogenetic analysis will give varying results. For a more in depth discussion on mosaicism please refer to: Taylor TH, Gitlin SA, Patrick JL, Crain JL, Wilson JM, Griffin DK, The origin, mechanisms, incidence and clinical

consequences of chromosomal mosaicism in humans. *Hum Reprod Update* 2014 Jul-Aug;20(4):571-81.

[5] Diagnostic error: less than 1%.

Appendix 2

IDENTIFICATION NUMBER:_____

STUDY QUESTIONNAIRE TO FACILITATE DECISION-MAKING ON GENETIC TESTING AND REPRODUCTIVE CHOICES

T0 Questionnaire

PRELIMINARY INFORMATION

Before completing this questionnaire please read the following points carefully:

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3. The purpose of the questionnaire is solely to assess how the participants' preferences are distributed with respect to the statements in the questionnaire.
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6. For the purposes of analysing the questionnaire, please **mark with an "X" only one answer**, and answer **all of the questions**.
7. Remember to always enter your identification number.

Before starting the questionnaire, please fill in the demographic information

GENDER: M / F

AGE: _____ years (number)

DEGREE:

- ☐ Medicine
- ☐ Nursing
- ☐ Physiotherapy
- ☐ Cognitive Sciences
- ☐ Philosophy
- ☐ Radiology

ABBREVIATIONS

PGD = PREIMPLANTATION GENETIC DIAGNOSIS

PD = PRENATAL DIAGNOSIS

QUESTIONNAIRE

Below each of the following statements, please indicate on the scale between 'Strongly Agree' and 'Strongly Disagree' the response that most accurately reflects your opinion. Please mark with an "X" the appropriate box.

Question 1

"A person who wants to have a child and suspects to be at risk of giving birth to an individual with a genetic disease can freely choose whether or not to verify this risk through genetic testing (i.e., he/she is not obliged to undergo genetic testing)."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 2

"A person who wants to have a child after being informed, following genetic testing, to be at risk of giving birth to an individual with a genetic disease, should not be directed towards any kind of reproductive choice (reproductive abstinence; adoption; heterologous fertilization; PGD and implantation in the uterus of unaffected embryos; conception, PD and therapeutic abortion) or given any kind of advice that is not purely informative. Instead, he/she should be free to choose which strategy to pursue."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 3

"A person who wants to have a child after being informed, following genetic testing, to be at risk of giving birth to an individual with genetic disease, should be forced towards a specific set of reproductive choices (reproductive abstinence; adoption; heterologous fertilization; PGD and implantation in the uterus of unaffected embryos; conception, PD and therapeutic abortion)."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 4

"From an ethical standpoint, to not implant an embryo affected by a genetic disorder or to abort a foetus with a genetic disease are equivalent actions. In each case, the formation of a new life is prevented".

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 5

"It is ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases, because in many cases it is the parents who will bear the greater burden of the unborn child's genetic disease."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 6

"It is ethically acceptable for parents to use PGD or DP with the aim of having a child free of genetic disease because, as prospective parents, they are obliged to give birth to a child who, among all those that they could have, is expected to have the better life (or at least as good as that of the others) based on the available information. Indeed, there seems to be a moral duty to not introduce unnecessary suffering in the world. "

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 7

"It is ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases considering that, in evolutionary processes, individuals best suited to the context in which they live have an advantage in their individual survival and in their production of fertile offspring."

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 8

"It is ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases, as this is consistent with the aims of medicine: to prevent and to cure disabilities".

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 9

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases, as it is not the fault of the embryo/foetus if it is suffering from a genetic disease. Not implanting or aborting an affected embryo/foetus will harm it unjustly. "

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
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Question 10

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because, by doing so, one assumes to have the right to choose who to allow or to deny the possibility of life."

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 11

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases in the case of low-penetrance diseases, as by doing so may eliminate a future individual who will not develop the disease."

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 12

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because the affected embryo/foetus has only two alternatives: to be born with the disease or not to be born at all. In fact, PGD/PD is not a therapy: the affected embryo/foetus is not treated; on the contrary, a healthy one is chosen in its place."

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
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Question 13

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because, by doing so, there will be fewer and fewer sick people in the world and therefore their voices and their rights will be less and less heard or considered to be politically relevant."

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 14

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because, in the long-term, this practice is likely to promote social rejection of people suffering from those diseases ".

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

HAVE YOU ANSWERED ALL OF THE QUESTIONS?
HAVE YOU FILLED IN YOUR IDENTIFICATION NUMBER?
PLEASE CHECK ONE LAST TIME!

Appendix 3

IDENTIFICATION NUMBER:_____

STUDY QUESTIONNAIRE TO FACILITATE DECISION-MAKING ON GENETIC TESTING AND REPRODUCTIVE CHOICES

T1 Questionnaire

PRELIMINARY INFORMATION

Before completing this questionnaire please read the following points carefully:

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11. The questionnaire focuses on the following subject: genetic testing in the context of reproductive choices.
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13. For the purposes of analysing the questionnaire, please **mark with an "X" only one answer**, and answer **all of the questions**.
14. Remember to always enter your identification number.

ABBREVIATIONS

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QUESTIONS TO EVALUATE THE PARTICIPANT'S UNDERSTANDING OF THE INFORMATIVE MATERIAL

Question 1

Genetic diseases include:

- All chromosomal disorders
- All chromosomal disorders, monogenic/single-gene disorders and multifactorial inheritance disorders
- Only monogenic disorders

Question 2

Genetic tests/analyses are able to:

- Determine only whether a person has a genetic disorder at the time of testing
- Determine only a person's predisposition to developing a specific genetic disorder
- Determine both of the above points, as well as individual genetic variations thereby allowing the selection of the most appropriate treatment for a specific individual

Question 3

Penetrance tells us:

- The relationship between genotype and phenotype for a specific genetic disease in a given population
- The relationship between genotype and phenotype for a specific genetic disease in a specific individual
- How severe a given disease will be in a specific individual

Question 4

Prenatal tests:

- Are performed on the embryo to determine whether it is affected by a specific genetic disorder
- Are performed on the foetus, already implanted in the uterus, during different stages of pregnancy to determine whether it is affected or not by a specific genetic disorder
- Are performed on the foetus, already implanted in the uterus, during different stages of pregnancy to determine whether it is affected or not by any of the known genetic disorders

Question 5

Preimplantation genetic diagnosis:

- Is performed on the foetus during the second month pregnancy to check for chromosomal abnormalities
- Is performed on embryos, created through various assisted reproduction techniques, before their implantation in the uterus to test for a given genetic disorder
- Is performed on embryos, created through various assisted reproduction techniques, before their implantation in the uterus to test for multifactorial inheritance disorders

QUESTIONNAIRE

Below each of the following statements, please indicate on the scale between 'Strongly Agree' and 'Strongly Disagree' the response that most accurately reflects your opinion. Please mark with an "X" the appropriate box.

Question 1

"A person who wants to have a child and suspects to be at risk of giving birth to an individual with a genetic disease can freely choose whether or not to verify this risk through genetic testing (i.e., he/she is not obliged to undergo genetic testing)."

- [ ] Strongly disagree
- [ ] Disagree
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Question 2

"A person who wants to have a child after being informed, following genetic testing, to be at risk of giving birth to an individual with a genetic disease, should not be directed towards any kind of reproductive choice (reproductive abstinence; adoption; heterologous fertilization; PGD and implantation in the uterus of unaffected embryos; conception, PD and therapeutic abortion) or given any kind of advice that is not purely informative. Instead, he/she should be free to choose which strategy to pursue."

- [ ] Strongly disagree
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"From an ethical standpoint, to not implant an embryo affected by a genetic disorder or to abort a foetus with a genetic disease are equivalent actions. In each case, the formation of a new life is prevented".

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"It is ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases, because in many cases it is the parents who will bear the greater burden of the unborn child's genetic disease."

- ☐ Strongly disagree
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"It is ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases considering that, in evolutionary processes, individuals best suited to the context in which they live have an advantage in their individual survival and in their production of fertile offspring."

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Question 10

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Appendix 4

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STUDY QUESTIONNAIRE TO FACILITATE DECISION-MAKING ON GENETIC TESTING AND REPRODUCTIVE CHOICES

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- ☐ Strongly agree

Question 13

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because, by doing so, there will be fewer and fewer sick people in the world and therefore their voices and their rights will be less and less heard or considered to be politically relevant."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 14

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because, in the long-term, this practice is likely to promote social rejection of people suffering from those diseases ".

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

HAVE YOU ANSWERED ALL OF THE QUESTIONS?
HAVE YOU FILLED IN YOUR IDENTIFICATION NUMBER?
PLEASE CHECK ONE LAST TIME!

EXPERIMENT'S EVALUATION

Please fill in the following table expressing your opinion on the experience.
Please fill in just one box for each question.

QUESTIONS	Not at all	Small degree	Moderate degree	High degree	Very high degree
*How much has the discussion you took part in, promoted an attitude of **higher respect towards the preferences of the other participants**?*					
*How has the discussion you took part in, **prompt your group to reach a consensus**?*					
*How much has the discussion you took part in, had **an impact on the transformation of your preferences concerning the issue at hand**?*					
*How much has the discussion you took part in, **allowed you to express your preferences in an unconstrained way**?*					
*Do you think you have been somehow manipulated towards a specific position **from the person who supervised the discussion**?*					
*How **clear** were the questions of the questionnaire?*					

Do you have any suggestion?

Appendix 5

IDENTIFICATION NUMBER:_____

STUDY QUESTIONNAIRE TO FACILITATE DECISION-MAKING ON GENETIC TESTING AND REPRODUCTIVE CHOICES

T3 Questionnaire

PRELIMINARY INFORMATION

Before completing this questionnaire please read the following points carefully:

22. The questionnaire is completely anonymous and the answers will be used only for statistical analyses.
23. When filling out the questionnaire, please note that there are no right or wrong answers.
24. The purpose of the questionnaire is solely to assess how the participants' preferences are distributed with respect to the statements in the questionnaire.
25. The questionnaire focuses on the following subject: genetic testing in the context of reproductive choices.
26. Choosing the response "I neither agree or disagree" may mean that you do not have sufficient information to answer the question, or that you are not yet certain of your preference (despite having sufficient information), or that there are other reasons for not giving (or being able to give) a definitive answer to the question.
27. For the purposes of analysing the questionnaire, please **mark with an "X" only one answer**, and answer **all of the questions**.
28. Remember to always enter your identification number.

ABBREVIATIONS

PGD = PREIMPLANTATION GENETIC DIAGNOSIS

PD = PRENATAL DIAGNOSIS

QUESTIONNAIRE

Below each of the following statements, please indicate on the scale between 'Strongly Agree' and 'Strongly Disagree' the response that most accurately reflects your opinion. Please mark with an "X" the appropriate box.

Question 1

"A person who wants to have a child and suspects to be at risk of giving birth to an individual with a genetic disease can freely choose whether or not to verify this risk through genetic testing (i.e., he/she is not obliged to undergo genetic testing)."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 2

"A person who wants to have a child after being informed, following genetic testing, to be at risk of giving birth to an individual with a genetic disease, should not be directed towards any kind of reproductive choice (reproductive abstinence; adoption; heterologous fertilization; PGD and implantation in the uterus of unaffected embryos; conception, PD and therapeutic abortion) or given any kind of advice that is not purely informative. Instead, he/she should be free to choose which strategy to pursue."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 3

"A person who wants to have a child after being informed, following genetic testing, to be at risk of giving birth to an individual with genetic disease, should be forced towards a specific set of reproductive choices (reproductive abstinence; adoption; heterologous fertilization; PGD and implantation in the uterus of unaffected embryos; conception, PD and therapeutic abortion)."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 4

"From an ethical standpoint, to not implant an embryo affected by a genetic disorder or to abort a foetus with a genetic disease are equivalent actions. In each case, the formation of a new life is prevented".

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 5

"It is ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases, because in many cases it is the parents who will bear the greater burden of the unborn child's genetic disease."

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 6

"It is ethically acceptable for parents to use PGD or DP with the aim of having a child free of genetic disease because, as prospective parents, they are obliged to give birth to a child who, among all those that they could have, is expected to have the better life (or at least as good as that of the others) based on the available information. Indeed, there seems to be a moral duty to not introduce unnecessary suffering in the world. "

- ☐ Strongly disagree
- ☐ Disagree
- ☐ Neither agree nor disagree
- ☐ Agree
- ☐ Strongly agree

Question 7

"It is ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases considering that, in evolutionary processes, individuals best suited to the context in which they live have an advantage in their individual survival and in their production of fertile offspring."

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 8

"It is ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases, as this is consistent with the aims of medicine: to prevent and to cure disabilities".

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 9

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases, as it is not the fault of the embryo/foetus if it is suffering from a genetic disease. Not implanting or aborting an affected embryo/foetus will harm it unjustly. "

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 10

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because, by doing so, one assumes to have the right to choose who to allow or to deny the possibility of life."

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 11

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases in the case of low-penetrance diseases, as by doing so may eliminate a future individual who will not develop the disease."

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 12

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because the affected embryo/foetus has only two alternatives: to be born with the disease or not to be born at all. In fact, PGD/PD is not a therapy: the affected embryo/foetus is not treated; on the contrary, a healthy one is chosen in its place."

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 13

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because, by doing so, there will be fewer and fewer sick people in the world and therefore their voices and their rights will be less and less heard or considered to be politically relevant."

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

Question 14

"It is NOT ethically acceptable for parents to use PGD or PD with the aim of having a child free of genetic diseases because, in the long-term, this practice is likely to promote social rejection of people suffering from those diseases ".

- [ ] Strongly disagree
- [ ] Disagree
- [ ] Neither agree nor disagree
- [ ] Agree
- [ ] Strongly agree

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HAVE YOU FILLED IN YOUR IDENTIFICATION NUMBER?
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